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ABSTRACT

Data were gathered from 154 U.S. programs providing personal assistance services for the disabled. The survey identified approximately 850,000 people receiving community-based, publicly-funded personal maintenance, hygiene, mobility, or household assistance services, with physically disabled individuals being the most often served. The report explores the growth in the need for personal assistance services, explains the World Institute on Disability's rationale for studying this situation, and identifies the potential user population. Background information describes several federal and state programs providing personal assistance services. Survey data includes such information as number of programs per state, year of implementation, goals, state agencies administering the programs, and their funding sources. Analysis of program structure focuses on eligibility, services, hours of service availability, maximum service amounts allowed, direct service providers, determination of services allowed, and medical supervision. Also examined is program conformity to the Independent Living Model, in which the personal services attendant is managed by the user and no medical supervision is required. The study analyzes service recipients and program expenditures, and compares the availability of attendant services across the United States. The report concludes with an analysis of the need versus adequacy of the system to meet that need and makes several recommendations. (JDD)

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ATTENDING TO AMERICA

PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

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Report Of

THE NATIONAL SURVEY OF ATTENDANT SERVICES PROGRAMS IN THE UNITED STATES

World Institute on Disability
April 1987

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ATTENDING TO AMERICA:
PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

A SURVEY OF ATTENDANT SERVICE PROGRAMS IN THE UNITED STATES FOR PEOPLE OF ALL AGES WITH DISABILITIES

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Special recognition must be given to the following WID staff members who made this project successful: Curtis "Kitty" Cone, who did the initial planning of the questionnaire and conducted part of the interviewing; Nancy Ferreyra, who conducted interviews, prepared the bibliography, assisted in data analysis, and answered correspondence and information requests; Hale Zukas, who was engaged in planning, editing and policy development at all stages of the project; Sandy Swan, who lent her computer and research skills and common sense; Marian Conning, who typed all the versions of the report, kept track of funds, offered sound suggestions and generally held down the fort; Helga Roth, who cheered us on and helped with editing; Joan Leon, who wrote the original proposal for the project and directed it through all its various stages; Mary Lester, who prepared the graphs; and Judy Heumann and Ed Roberts, who provided the ideological/philosophical overview for the project and the report. In addition, we would like to thank Carol Silverman, Ph.D., Instructor in Sociology at the University of California, Berkeley, who all but donated her research and computer skills to this project.

Simi Litvak
Berkeley, California
January, 1987

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* Individuals who use personal assistance services

PREFACE

By Irving Kenneth Zola, Ph.D.,
Department of Sociology, Brandeis University

Independence and self-reliance are strongly held American values. They are the key to any claim that we are a truly open society. For it is reasoned that if anyone would only try hard enough, s/he could eventually succeed -- the Horatio Alger myth. That such concepts have also crept into our rehabilitation literature should be no surprise. Thus traditional stories of successful rehabilitation continually stress the individual's ability to overcome his/her particular chronic disease or disability. In turn, individual qualities like courage, virtue, stick-to-it-ness, and the desire to "go it alone" were the very praiseworthy personal characteristics; and high scores on such scales as The Adaptation in Daily Living (ADL) (which measured the individual's ability to do many personal care activities by him/ herself) were the behavioral ones.

The founders of the Independent Living Movement were very different sorts of people. Their scores on the ADL scales were near the bottom and they were people on whom traditional providers of care had given up -- people for whom not only a productive life but even a meaningful one was deemed impossible. Neither they nor their families accepted the judgments of experts and in their struggle and their answer the Independent Living Movement was born. Their stories of success are different. Without negating the importance of personal qualities and the

improvement of one's functional abilities, they emphasized the necessity of removing architectural barriers, changing societal attitudes, and using help whenever and wherever they could get it.

In all the years I've heard Ed Roberts speak (To those who don't know him, he's one of those "rejects" mentioned above -- a man, post-polio, who uses a respirator and a wheelchair and was deemed unworthy of California's rehab dollars. He went on to co-found The California Center for Independent Living and later the World Institute on Disability and in-between became California's Commissioner of Rehabili tion and a MacArthur Fellow), before beginning, he introduces is personal assistants by name and briefly details the latter's role in Ed's being "here." This gesture concretizes a cornerstone of the whole Independent Living Movement (DeJong, 1983). Independence is not measured by the quantity of tasks we can perform without assistance but the quality of life we can have with help. People have often gotten help from others but it was often given in the context of duty and charity (Scotch, 1984). Help in the context of Independent Living is instead given within the framework of a civil right and a service under the control of the recipient -- where, when, how and by whom.

This cornerstone of the Independent Living Movement has long been argued about but little studied. DeJong (1977) surveyed the services of one state; DeJong and Wenkler (1983) did a comparison of several; and Laurie (1977), a timely national overview.

Within the last three years DeJong (1984) and Ratzka (1986) have provided in-depth descriptions of the progress and promise in the Netherlands and Sweden. This current report, prepared by Simi Litvak and sponsored by the World Institute on Disability, is a much needed American response -- a detailed survey of all the United States which gathered data from some 154 attendant service programs serving almost a million people. Though people with physical disabilities were those most often served, the programs also included ones serving those with brain injuries, intellectual and emotional problems. The 17-page questionnaire measured their development, administration, funding sources, and degree of conformity to the ideal Independent Living Model. Despite the wealth of data, this report is no mere compilation of tables and statistics. It is an extraordinarily self-critical document, telling the reader what it gathered well, poorly, and not at all. It names names and articulates issues. While echoing the need for further information, in a series of recommendations it lays down the gauntlet of what must be done to make all our citizens independent. While documenting the programs already in existence, it also describes the underserved and points to the future (the ever increasing number of newborns with disabilities as well as increasing aging of our population). It is clear that many who will read this report will not at present have a disability. But if the data on aging and genetics are correct, it is unlikely that anyone reading it will not in their lifetime have to face the issue for him/herself or in his or her families.

But at long last, we now have some baseline data. Personal Assistance for Independent Living lays down how far we have come and how far we have yet to go.

REFERENCES

DeJong, Gerben. (1977). Need for Personal Care Services by Severely Physically Disabled Citizens of Massachusetts. Personal Care and Disability Study, Report No. 1 and No. 2. Waltham, MA: Levinson Policy Institute of Brandeis University.

DeJong, Gerben. (1983). "Defining and Implementing the Independent Living Concept" in Nancy Crewe and Irving Kenneth Zola (Eds.). Independent Living for Physically Disabled People, pp. 4-7. San Francisco: Jossey-Bass.

DeJong, Gerben. (1984). Independent Living and Disability Policy in the Netherlands: Three Models of Residential Care and Independent Living. Report No. 7. New York, NY: World Rehabilitation Fund.

DeJong, Gerben and Wenker, Teg. (1983). "Attendant Care" in Nancy Crewe and Irving Kenneth Zola (Eds.). Independent Living for Physically Disabled People, pp. 157-170. San Francisco: Jossey-Bass.

Laurie, Gini. (1977). Housing and Home Services for the Disabled. New York, NY: Harper & Row.

Ratzka, Adolf D. (1986). Independent Living and Attendant Care in Sweden: A Consumer Perspective. Report No. 34. New York, NY: World Rehabilitation Fund.

Scotch, Richard. (1984). From Good Will to Civil Rights. Philadelphia: Temple University Press.

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CHAPTER I

INTRODUCTION

The need for community-*based personal assistance services* for independent living and the lack of a nationwide policy direction and mechanism for meeting the need has become an issue of major significance for disabled people of all ages who feel these services are critical to their ability to control their lives. Along with people who are disabled and their families, advocates, legislators and social policy makers throughout the United States and abroad have placed personal assistance services at home and in the community on the national agenda.

Personal assistance involves assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability.[1]

The survey, which is the subject of this report, indicates that there are approximately 850,000 people receiving some sort of community-based, publicly-funded personal maintenance and

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[1] These tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation laundering and long term heavy cleaning and repairs; 4) infant and child related tasks such as bathing, diapering and feeding; 5) cognitive or life management activities such as money management, planning and decision making; 6) security-related services such as daily monitoring by phone; and 7) communication services such as interpreting for people with hearing or speech disabilities and reading for people with visual disabilities.

hygiene, mobility and household assistance services. On the basis of the National Health Interview Survey and surveys of people who are institutionalized, we estimate that there are an additional three million people who could benefit from such services, but who currently are not receiving them from community-based, publicly-funded programs (Czajka, 1984, pp. 13-17). In other words, for every person who is actually receiving community-based, publicly-funded personal assistance services, there are three people who could benefit from such services but who are not receiving them.

Moreover, almost all the service programs which do exist are inadequate. Seldom do they offer the combination of personal assistance services necessary to enable people who are disabled to function satisfactorily at home and in the community. Distribution of these programs is uneven across the United States, eligibility criteria vary widely, and direct service providers are poorly compensated.

The Need for a National Personal Assistance Program and Policy

The need for personal assistance services has grown over the last few years because of several factors. First, the past few decades have seen major advances in medical technology. These advances have increased the ability to treat people who have experienced serious trauma, illness and birth-related disability, with the result that many individuals who would have died in earlier years are now surviving. Many of these people, however, end up with disabilities which interfere with their ability to perform activities of daily living independently.

Second, declining mortality and lengthening life expectancy have meant that an ever-increasing number of people in the U.S. population are old people (Van Nostrand, 1984). This demographic shift in itself has expanded the disabled population, since loss of functional ability (i.e. ability to perform activities of daily living) often accompanies the illnesses and injuries that occur more commonly among older people. The survey upon which this report is based shows that at least 77% of the people currently receiving personal assistance services are older people over the age of 60 or 65.

Third, the demand for personal assistance services has expanded as a result of the growing emphasis on keeping and taking disabled and elderly people out of institutions. Custodial institutions are no longer an accepted means of meeting the personal assistance needs of disabled people of any age. This shift in attitude coincided with the emergence of the Independent Living Movement which, in conjunction with advocacy groups, was organized to foster independence and minimize the dependence of disabled people.

In the fifteen years since the first Independent Living Program run by disabled people was founded in Berkeley, California, over 200 such programs have been established across the country. A top priority of the Independent Living Programs has been to get and keep disabled people out of institutions. It was very clear to these activists that, on the one hand, the successful deinstitutionalization of people with extensive disabilities, as well as the prevention of institutionalization

and avoidance of dependency, rested substantially on the availability of personal assistance services in the community. But, on the other hand, the existing service system lacked a strong community-based orientation and therefore did not offer the services that foster independence.

Beginning in the late 1960's, people with mental retardation, along with their families and advocates, successfully pushed for normalization of the lives of people with intellectual disabilities. Over the past two decades many large state institutions for people with intellectual disabilities have been closed or had their populations greatly reduced. Various types of small group living arrangements have been established in communities to take their place.[2]

There has been a similar deinstitutionalization trend in the treatment of people with mental or psychiatric disabilities. Community treatment for people with mental disabilities was promoted in the late 1950's and 60's and the large state hospitals discharged vast numbers of patients to an uncertain existence in cities all across the U.S.

Fourth, the emphasis in meeting the needs of older people has shifted from institutional care (particularly nursing home care) to home and community based assistance. Older people and their advocates are waging a struggle to develop a "continuum of

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[2] More recently, living arrangements offering greater degrees of independence have been established where assistance with activities of daily living is provided only to the extent needed. For example, a number of people may live in a small apartment complex and share the services of an assistant who comes in as needed to help with paying bills, filling out forms, shopping and so on.

long term care" where nursing homes are only one of several elements, rather than the primary locus of assistance for older people with functional limitations. In some states the establishment of new nursing homes has declined greatly, though this has not always been accompanied by the development of community-based services.

A fifth factor increasing the demand for personal assistance services has been the transformation U.S. families have undergone over the past several decades. Changes have occurred which have made families less able to take upon themselves the job of providing personal assistance to their disabled members. A majority of working-age women now hold jobs outside the home. Rising divorce rates, shrinking family size and the growth in single-parent families have all contributed to the family's decreasing ability to provide personal assistance services for their disabled members of all ages (Oktay & Palley, 1983). From an Independent Living standpoint, moreover, it is often undesirable for family members to provide such services, even if they are able to do so. Employing a personal assistant allows all the family members more freedom and enables the member with a disability to function as an autonomous being rather than remain in a relationship that fosters dependency.

Finally, during the late 1970's and early 1980's, the federal and state governments became very interested in the replacement of institutional care by community-based services, which include personal assistance services, because this seemed to be a more economical way to treat disabled people unable to

manage completely for themselves.

The need for community-based personal assistance services, then, is clearly on the national agenda. Despite the growing need and interest, however, the federal government has neither promoted the development of these services nor established a coherent policy on the issue.[3] Jurisdiction over various personal assistance programs and policies is divided among numerous federal agencies and congressional committees. There is no coordinated "system".

In the absence of a comprehensive federal policy and funding for personal assistance services, some states have tried to piece together several federal funding sources into a state program; a few other states have tried to meet the need by developing their own policy and program; still other states have done nothing in the area and, as a result, have almost no personal assistance services available.

The lack of a comprehensive, coordinated national policy often means that, even where the services are available at all, users either have to maneuver through a fragmented maze of service programs in order to put together a package of required services, make do with services that are inadequate, or remain in an institution, nursing home, or isolated at home with their families.

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[3] In contrast, a nursing home policy does exist. Currently the government, through Medicaid (see Chapter II), will pay for people who are disabled and who meet the income guidelines to live in nursing homes for the rest of their lives. Clearly a policy for personal assistance services would greatly reduce the need for nursing homes for such people.

In addition, those programs that do exist usually provide assistants only for poor people. This means that people either need to have incomes below the poverty level or they need to earn enough not only to support themselves but also to pay for an assistant. The resulting need to earn a relatively high income thus discourages people from working, thereby increasing, rather than decreasing, public expenditures on the disabled.[4]

Why WID is Studying Attendant Services

The World Institute on Disability is well equipped to examine the issues surrounding personal assistance services because its staff thoroughly recognizes, from a number of perspectives, that personal assistance services are often the key to Independent Living for people of all ages with moderate and extensive disabilities. In the first place, those staff who use assistants have, of course, learned the importance of personal assistance services in their lives. Second, several staff members have held key policy positions in state or federal

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[4] These disincentives to employment built into the current attendant service eligibility requirements should eventually be eroded by Section 1619 of the Social Security Act which was made permanent in November of 1986 and which takes effect June 1987. Under Sec. 1619, disabled people already receiving SSI who go to work are now allowed to retain Medicaid-funded medical benefits and federally-funded attendant services, where they exist, as long as the disabled individual: 1) continues to meet the SSI resource or asset limits, and 2) his or her earnings do not exceed a "reasonable equivalent" of the combination of previous SSI payments, Medicaid medical benefits and publicly-funded attendant services. In addition, individuals may shift back onto full SSI benefits if for some reason the job does not continue. Unfortunately, people receiving personal assistance services from solely state-funded programs may not necessarily retain these services unless the state links eligibility to SSI eligibility. Obviously, Sec. 1619 will have no impact on the bulk of personal assistance service users, i.e. people over ages 60 or 65.

government and have an appreciation of the pluralistic nature of the policy process and the role the respective levels of government, as well as the private sector, play in setting social policy. Third, WID was established by several founders of the Independent Living Movement in order to examine public policy issues from the perspective of that movement. Fourth, the Institute is located in California, which has the oldest and largest publicly-funded personal assistance service program in the country.[5]

We are asked continually by people with disabilities how the California system can be used as a model in other localities. We are acutely aware of the dearth of adequate personal assistance services in most other parts of the country despite the growing demand for those services. It is clear that the lack of satisfactory personal assistance services is a major obstacle preventing many people with disabilities from achieving the goal of living independently.

On the one hand, then, the WID staff know well the pivotal importance of personal assistance services to people with a wide range of disabilities. On the other hand, they have also been very aware of the inadequacy and spotty distribution of personal assistance services across the country and of the complete absence of information on the nature and extent of those services

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[5] This is no coincidence. We believe, in fact, that the first Independent Living Center was established in California because the well-developed California personal assistance service system provided disabled Californians, including many of the WID staff, the services they needed to enable them to meet and work together for independence.

that do exist. These considerations led the World Institute on Disability to undertake a survey of every publicly-funded personal assistance program in the country offering personal maintenance, hygiene, mobility and household assistance services in order to provide for the first time an accurate and comprehensive picture of the state of these key services in the United States today. This report presents the findings of that survey.

Other significant sectors of the disabled community, as well, are recognizing personal assistance services as an issue whose time has come. The National Council on the Handicapped (NCH), a body which advises Congress and the President on policy issues related to disability, has selected personal assistance services as one of its priority issues. We have relied on the results of their conferences on personal assistance services, which WID helped organize, in conducting this research.

We believe that the data presented in this report begins to provide a basis on which the National Council on the Handicapped and other policy makers, planners, and consumer organizations can evaluate the current policies and services and determine what needs to be done to develop an adequate and equitable national system of personal assistance services for all those who need them.

The Concept of Personal Assistance and Attendant Services

This report covers the availability of attendant services only. Attendant services are a subset of the full range of personal assistance services disabled people need to function

independently in the community (see footnote 1, page 1, and Nosek, 1986). Attendant services include assistance with personal hygiene, mobility and household maintenance tasks. Often these services are separated into groups and offered by separate programs. To compound the confusion, they are called by other names as well: personal care services, personal care attendant services, home health aide services, homemaker services, chore services.[6] (See Appendix A for some definitions.)

Our conception of appropriate personal assistance services goes much deeper than a simple listing of tasks, however. Of major importance is that personal assistance service users have the opportunity, if desired, to exercise as much control as they are capable of handling over the direction and provision of these services - i.e. who does them, how, and when. This concept of personal assistance is the Independent Living Movement's preferred model of service provision. The model rests on the philosophy that to be independent means to be empowered and self-directed. Independence does not mean that one must be able to perform all tasks alone without help from another human being. This distinction may appear to some as not very significant, but it is absolutely crucial for people of all ages with extensive disabilities. Such individuals may be able to perform few if any

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[6] In discussing and defining personal assistance and attendant services, we deliberately avoid the use of the term "care" (e.g. attendant care, personal care, etc.) because it implies that the disabled person passively receives the ministrations of the attendant. In our view, care is what sick people receive. Disabled people are not sick and, therefore, do not need "care". They need an assistant.

daily living tasks without assistance, but this fact has no bearing on their right to determine when, where and how these tasks are performed. For people who are unable or unwilling totally to direct their own services, the option to receive services from assistants who are trained and supervised by a public or private agency should be available.

In addition, personal assistance services are personal assistance services even when they are performed by members of one's family. Consequently, family members who provide such services at the request of the user deserve to receive compensation for their labor. People with extensive disabilities may require 20 or more hours of assistance per week, the equivalent of a half-time job. This amount of assistance, which is quite beyond what family members would do for each other if none were disabled, clearly cuts into the time that would otherwise be available for outside employment and other familial duties. The vast majority of people who provide volunteer personal assistance in the U.S. are women (Reaser, 1985). In particular, most of these volunteers are middle-aged women performing attendant services for an aging parent, because most of the people requiring personal assistance are older people. These volunteer assistants are often prevented from seeking paid employment, a situation which greatly contributes to poverty among women. Clearly, when families maintain disabled members outside of institutions, they may save the government much money, but providing these services on a volunteer basis substantially reduces the family's earning potential and may limit the person

with a disability from achieving full independence. Having to depend upon the charity or good will of family and friends places the user in a dependent rather than an independent position. In addition, when family members are forced by economic or other reasons to provide attendant services, the resulting stress can lead to psychological or physical abuse of the person who is disabled.

The Independent Living conception of attendant services also recognizes the need to augment regular service delivery systems with both emergency and short-term services, commonly referred to as respite. Emergency attendant services provide assistants in cases of emergency, for example when attendants cannot perform their duties because of sickness or personal difficulties and not enough notice can be given to make other arrangements. In cases where a disabled individual lives alone and has no relatives or friends who can help out at the last minute, emergency back-up services are crucial.

Short-term services are intermittent attendant services replacing family members or regular assistants on a scheduled basis. They enable the individual who is disabled to get both the assistance needed and an opportunity to be independent of the family for brief periods. Short-term personal assistance also allows the family member to leave the home for anything from a few hours for errands to an evening out or several weeks' vacation. Emergency and short-term workers should be trained so they can go into a variety of situations, including homes with non-directing disabled persons. Pools of such workers should be

available.[7]

Finally, personal assistance services are only a part of the "Complex Cube of Long Term Care" which "includes the areas of health care, social services, housing, transportation, income security and jobs" (Oriol, 1985, p. 15). Personal assistance services by themselves are not sufficient to enable people with disabilities to live to their maximum potential in the community but they are absolutely necessary to achievement of this goal.

Potential User Population for Attendant Services

The population of potential users of attendant services is large and diverse. It includes people of any age and with any disability - be it physical, sensory, intellectual or mental- which results in long-term functional limitations that impair an individual's ability to maintain independence (see Zola, 1986 for a fuller discussion).

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[7] Short-term services are part of the continuum of personal assistance services. Some people need these services daily, some need them several times a week and others need services on occasions when family members have to leave the home. Short-term services serve the person who is disabled by breaking the chain of mutual dependency between the disabled family member of any age and the rest of the family. Power dynamics in families can be changed by another person coming into the home for brief periods. Because families may have to provide major amounts of service, the disabled individual may be made the victim of the family's stress. In these situations, the disabled individual needs a break from the family and the routine equally as much as the family. Short-term personal assistance should be seen as an opportunity for the disabled individual to get out of the house, go on visits, see a film or even take a trip. Usually the family goes away for a good time and the disabled person stays at home or, even worse, is sent to a hospital.

The notion of who needs or can use an assistant has expanded in the last few years. It is generally accepted that people with physical disabilities often need assistance. More recently, however, people with mental or intellectual disabilities but no physical limitations have also begun to use assistants to help them function effectively in the community. Such assistants may help people pay bills, keep financial records, make up shopping lists, deal with landlords, etc.

The user population includes people of all ages. There has been a tendency to treat older people with functional limitations, disabled working age people and disabled children as three distinct groups with totally different service needs. However, older people who have functional limitations are disabled in the same sense that younger disabled people are-that is, they are limited in their ability to perform life-maintaining tasks without assistance. Whether young or old, disabled people may be at risk of isolation, physical harm and institutionalization because of their functional limitations. The causes of these limitations may vary somewhat, but the effects are often very similar. Furthermore, older people with functional limitations have as much need to maintain control over their lives and the services they receive as younger people with disabilities. Thus, not only are personal assistance services often the appropriate answer for many older people with disabilities, but the principles of the Independent Living Movement apply to them as well.

If personal assistance has not been widely recognized as a

means of fostering older people's independence, the use of non-family paid providers to foster independence in disabled children has hardly even been considered. Making such assistance available has several benefits. It can alleviate financial pressure on families by allowing parents to take outside employment. This is particularly true in cases where a child with a disability needs assistance throughout the day and there are no volunteer resources available.

Second, personal assistants for children can relieve the emotional strain that frequently develops within families as siblings (and sometimes parents) come to resent the disproportionate amount of time that parents must devote to a child who is disabled.

Finally, providing personal assistants for children with disabilities allows them a more normal process of development and maturation. It allows them to go places (thus gradually expanding their range of mobility), engage in recreational pursuits, and-particularly important during adolescence - interact with peers. Also, children with disabilities, assisted by an attendant, can begin taking on family chores and duties - such as setting the table or taking out the garbage - just as non-disabled children do as a normal part of growing up.

This list of benefits obtained by providing attendants for children of all ages could go on and on. The primary point, however, is that the process of developing one's independence and self-management skills commences long before a person with a disability reaches adulthood. It is a process that occurs

throughout the normal course of development that all children go through.

Not only does the Independent Living view of the potential attendant service user population include people of all ages, it also includes people in various living arrangements. People with functional limitations who live independently obviously need assistance. People living with their families also need assistance; whether in the form of occasional short-term services or on a regular basis, so that the disabled person has more independence and the family member, relieved of attendant duties, is free to work and/or maintain the home. Attendants may also work for clients in various congregate living arrangements such as cluster housing and group homes. In these situations, attendants may be shared by several people, though this type of arrangement has drawbacks because it frequently means that the individual user loses control over when and how long the attendant is available.

In addition, people can use personal assistance not only at home but also at work, recreation and travel.

Corollary to this inclusive definition of who can benefit from personal assistance services is the proposition that the medical diagnostic category a person falls into should have no bearing on his or her eligibility for services, since people with similar diagnoses may have dissimilar functional abilities and face different sets of environmental constraints. Determination of need for personal assistance should be based on a functional assessment which measures one's abilities and limitations in

performing necessary activities of daily living within a particular environment.

Overview of the Survey

This report is based on the results of a survey - conducted by mail or telephone from February 1985 to January 1986 - of administrators of every program in the United States (excluding Puerto Rico and the U.S. territories) which provided personal maintenance and hygiene and/or household assistance services on either a regular or short-term basis.

Programs for disabled people of all ages were included except those exclusively for people with mental disabilities ("mental illness") and/or people with intellectual disabilities ("mental retardation"). Because of fragmentation of the service system, these programs are administered separately and would have required substantial additional resources to locate and survey. One-hundred seventy-three programs meeting these criteria were identified. Nineteen of these, for various reasons, are not included in the results presented here.[8] A detailed discussion of the survey methodology can be found in Appendix B. A copy of the questionnaire is in Appendix C.

The questions addressed by WID's survey and by this report are the following:

1. What are the goals of the programs? How are the programs structured? What are their administering

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[8] Throughout this report, when a table refers to data from fewer than the 154 programs in the data set, the actual number of programs responding to that item has been noted.

agencies, funding sources and eligibility criteria? What services are provided and who provides them?

2. How well do the programs meet scope and quality criteria for an adequate attendant services system developed by the participants at the July 1985 conference in Washington, D.C. sponsored by the National Council on the Handicapped in conjunction with the World Institute on Disability?

3. Where do programs fall along the continuum between the Independent Living and medical models? (See p. 67 for description of program models.)

4. What is the degree of attendant service utilization, i.e. how many people are currently receiving some type of attendant services? How does this number compare to the number of people who could benefit from such services?

5. Are attendant services equitably distributed across the U.S.?

CHAPTER II

DEVELOPMENT OF PERSONAL ASSISTANCE SERVICES IN THE U.S.

There are several federal and state programs that currently provide at least part of the constellation of personal assistance services needed by people who are disabled. The oldest and largest arose with the development of the U.S. social welfare system, in particular the 1965 amendments to the Social Security Act which established Medicaid (Title XIX) and the 1974 amendments which created Title XX, which in 1981 became the Social Services Block Grant program.[9]

Medicaid - Title XIX

Medicaid was established to provide medical assistance to low-income people of all ages. There are no federal funding limits. The program is financed jointly by federal and state funds, with the state's share varying from 22.5% to 50%. In addition, the bulk of Medicaid funds go toward hospital, nursing home and institutional services. States are required minimally to deliver health-related home services from a certified Home

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[9] Medicare (Title XVIII of the Social Security Act) was also created in 1965 to provide health insurance benefits, primarily for those eligible for Social Security Retirement Benefits. Until recently, it provided medically related services to homebound people for a very limited period, post hospitalization. In the early 1980's the limitations on number of visits was removed. Though this obstacle has been removed, the "homebound" and "medically related" provisions remain. The homebound provision requires that recipients be so ill or disabled that they seldom if ever leave the house. And the medically related provision requires that all services provided must be certified by the physician as relating to maintenance of the individual's health. Even if interpreted liberally, these provisions continue to make Medicare a dubious source for personal assistance service dollars.

Health Aide or Registered Nurse. Beyond this minimum there are wide variations from state to state in home and community-based service benefits offered, groups covered, income eligibility criteria, cost sharing formulae and levels of provider reimbursement. States have the option to provide, in addition to home health services, "personal care services" in the home - such as dressing, feeding, bathing, ambulation and transfers - from a less skilled provider on a long term basis.

Even with the "personal care" option and the Medicaid Home and Community-Based Services Waivers (see page 23), the thrust of Medicaid home-delivered services is still heavily weighted toward medically related services. Programs require frequent supervision by a Registered Nurse. Physicians must certify that services are in some way related to maintenance of an individual's health. Personal assistance services have to be delivered by certified Home Health Aides or less skilled agency-trained, not user-trained, individuals.

A few cities and states have found innovative ways to work within the medically oriented Medicaid framework and still make it possible for individuals who are disabled to maintain a great deal of control over who delivers the service and how it is delivered. In Denver, Boston, New York City and a few other areas, the Independent Living Programs have been designated as Home Health Agencies. They in turn allow disabled people to hire and train their own assistants, with Center approval, and some even pay the assistant's wages directly to the consumer who then pays his or her own assistant.

Title XX and Social Services Block Grant (SSBG)

Between 1975 and 1981, Title XX of the Social Security Act provided funding for four social service program goals, one of which was the prevention of institutionalization by providing community or home based services including homemaker, chore and home health aide services.[10] Title XX was restructured in 1981 as a block grant to states, generally allocated on the basis of the state's population, with no state matching requirement. Since 1975, however, the funding level for Title XX/Social Services Block Grant (SSBG) has been raised very little, from $2.57 billion in 1976 to $2.7 billion for 1984, 1985 and 1986.

Under the block grant, each state designs its own mix of services and determines eligibility requirements. In general, however, states still use SSBG for services to the poor. The exception is protective and emergency services directed at preventing abuse of children or adults, which are provided without regard to income and which include personal assistance.

Most of the states still provide home based services of some sort using SSBG monies, but few have developed comprehensive SSBG attendant services programs which encompass personal maintenance, hygiene, mobility and household assistance. California's In-Home Supportive Services system (IHSS), with expenditures of $370 million in FY85-86 and a case load of 111,300, is a notable exception.

It is also common for states to combine Medicaid funds for "personal care" with SSBG monies for household assistance either

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[10] See Appendix A for definitions.

in one program or in a service package for an individual who requires both services. The latter arrangement occurs in states with less developed social/health service systems and is the least desirable because the disabled consumer must deal with two different providers and with two different sets of regulations and administrative staffs.

Older Americans Act - Title III

The most recent social welfare program offering personal assistance services was established under Title III of the Older Americans Act. Title III was designed to either augment existing services or to develop new ones to meet the needs of people over 60 years old. Unlike Medicaid and SSBG programs, there are no income eligibility rules for Title III, though federal regulations encourage local Area Agencies on Aging to target poorer people, as program funds are limited.

The program requires that states expend an "adequate proportion" of their allotted funds for a wide variety of services, including personal assistance services such as "personal care", chore, housekeeping, shopping, interpreting and translating, repairs/maintenance/renovations, escort and letter writing or reading, unless the state agencies can demonstrate that such services are already adequately available through some other source. In general, the Area Agencies on Aging supplement Medicaid and Title XX funding for home care services with Title III funds. In addition, states receive separate allotments for home-delivered and congregate meals for older people, services which by themselves may enable a person to remain independent in

his or her own home.

Although Title III programs have grown since the early 1970's, Title III funds are limited and cannot begin to fill the need for the myriad of services Title III recognizes as necessary to prevent unnecessary and debilitating institutionalization or isolation within the home, including legal services, information and referral and nursing home ombudsmen programs. Given the breadth of Title III services, even a large increase over the existing funding allocation cannot go far. Another difficulty with Title III is that personal assistance services under Title III, where they do exist, are offered solely by Contract and Government agency workers, the least user controlled service delivery systems and the most expensive. However, it is important to note that while Title III seems to provide personal assistance services for very few people at this time, it is a very enlightened policy. Unlike the other funding sources, Title III actually includes services for people with all types of disabilities - physical, mental, intellectual, communication and sensory. Thus readers, interpreters and companions are included in the service package.

Medicaid Waivers

A major attempt to investigate ways to halt the growth of Medicaid expenditure, the largest proportion of which goes toward institutional and nursing home care of people with intellectual disabilities and older people in particular, was the development of the Medicaid Waiver program in 1979. States can apply for a Waiver of the regular Medicaid rules to deliver a variety of home

and community-based services to older people or people with emotional or intellectual disabilities in order to avoid institutionalization. An assumption underlying the waiver programs was that home and community based services are less costly than institutional services. Among the services which are provided by waiver programs are attendant and short-term (respite) services. Under this program states can waive the usual Medicaid requirements with approval of the Health Care Financing Administration (HCFA), including broadening the array of services offered, liberalizing income eligibility for parents of eligible children and providing services only to certain populations.

Currently there is considerable tension between the Health Care Financing Administration (HCFA) and the states regarding use of the Waivers. States are using Waiver monies to increase development of noninstitutional services. Theoretically the availability of more community and home health services could cut down on nursing home costs, but the U.S. Government Accounting Office (1982) argues that increased demand could offset any savings. Consequently federal authorities, whose major concern is controlling Medicaid expenditures, have tried to reduce greatly the number of people who can be covered by the waivers. These officials argue that, since the number of people who would ordinarily be in a nursing home is limited to the number of nursing home beds which exist in any particular state (an amount which varies widely), then the number of people on the waiver must be limited to those who quite literally would be admitted to a nursing home if it weren't for the waiver. Since those who

aren't admitted because of bed shortages somehow get their needs met in other settings by family and friends, the argument goes, the federal government has no responsibility to maintain these people.[11] In addition, the federal government requires states not to spend on any one individual more than the average cost of what it takes to maintain people in nursing homes, less a certain percentage for room-and-board costs. This last rule discriminated against people with extensive disabilities because the bulk of people in nursing homes are older people with fewer service needs and presumably lower average service costs. Responding to pressure, Congress has now changed this rule so that there is a two-tiered limit - one the average cost of maintaining physically disabled people and the other the average cost of maintaining other nursing home residents (Consolidated Omnibus Budget Reconciliation Act, 1985).

In contrast to the federal government's position, state administrators, who face a growing demand for home-delivered services, originally viewed the waivers as the opening of a way to expand Medicaid coverage to very comprehensive home/community based services for all who need it. At this point, unfortunately, the federal government is using its approval authority to deny or impede applications for and renewals of waivers (Association for Retarded Citizens, 1985, pp. 6-7). As a result,

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[11] Emma Gunterman, Senior Advocate for the California Rural Legal Assistance Foundation, in a private communication (1986) stated that "it is a myth that all of these persons have relatives and friends and, if they have them, that they can give that level of care. Persons who physically qualify for nursing facility care often end up in County Hospitals."

comparatively few disabled people are served through the waiver programs.

Solely State and Locally Funded Programs

The development of Medicaid Waiver Programs coincided with the establishment of a number of state-funded, consumer oriented programs, largely as a result of the development of the Independent Living Movement. In the past 20 years there had been a sharp increase in the number of young people with extensive disabilities, people who in earlier periods would most certainly have died of respiratory complications and spinal cord injuries in particular. Increased survival rates occurred because of advances in medical technology made in response to the polio epidemic of the 1950's, World War II, the Korean War and the Vietnam War as well as major progress in intensive care and emergency medical technique in the late 1970's and the 1980's. Once stabilized medically, many of those who survived faced a full lifetime in a nursing home, dependence upon their families until the parents become too old to provide the necessary attendant services, or dependence upon service programs that encouraged dependence and poverty.

Those attendant service programs which existed for non-veterans were only available from home health agencies or government workers to those whose income and assets were at or near the poverty level. People with extensive disabilities faced a dilemma. They either had to earn a substantial income in order to pay for a user-directed personal assistant and other disability related expenses out of pocket, or they had to not

work at all and receive federal disability income in order to qualify for Medicaid and SSBG services which provided personal assistance according to the hours and plans of the assistant. For many people with disabilities, as for most members of our society, earning a high income is not an achievable goal. And it is even less achievable for people with extensive disabilities who may be able to work only part time or have inadequate education. As a consequence, publicly funded personal assistance services which would allow an individual to live in his or her own home with maximum personal control over how services are delivered combined with the opportunity to work as much as possible became a major goal of the Independent Living Movement.

During the late 1970's and early 1980's, a number of states responded to this need by creating personal assistance service programs funded entirely by state and local sources which not only allowed disabled people to hire, train and, if necessary, fire their own assistants but also had realistic cost-sharing formulae allowing people with disabilities to work and still receive a personal assistant subsidy payment.

Veterans' Aid and Attendance Allowance

In addition to Medicaid, SSBG, Title III and state-funded personal assistance programs, there is also the "Aid and Attendance Allowance" furnished to Veterans in addition to their monthly compensation for disability incurred during active service in the line of duty (Title 38, 1984). Eligible veterans in need of regular aid and attendance received either $906 or $1,350 (if they were at risk of institutionalization) to purchase

the service of a personal assistant who is either a family member, hired through an agency or is an individual provider. The individual receiving the higher rate of compensation is considered to need "personal health-care services" which must be provided by a person either licensed to provide these services or supervised by a licensed health care professional.

Beyond the various federal and state programs offering part of the constellation of services currently available, another factor shaping the nature of personal assistance service programs in the U.S. is the socio-economic situation of the individual states. Since the eligibility requirements, services delivered and levels of provider reimbursement are determined on the state level for all programs except those for veterans, the level of prosperity in the state and its orientation toward social welfare programs play a major role in determining who has access to personal assistance services. In general, social service programs of all kinds, including personal assistance services, are very sparse in the Southwest and Southeast. Some states have one or two major programs that serve all ages and disability groups, e.g. Illinois and California; others have several programs which target special groups or which must be combined to deliver an entire service package.

Much of the survey data presented in the following chapters will serve to expand this discussion by presenting the current state of personal assistance services in the U.S.

CHAPTER III

PROGRAM GOALS, ADMINISTRATION AND FUNDING

There are 173 programs in the U.S. that offer comprehensive or selected personal assistance services on a long-term or short-term (respite) basis. As shown in Table 1, 154 (89%) of these were included in the survey results.[12] This chapter gives an overview of the number per state, their year of implementation, the goals of these programs, the state agencies administering the programs, and their funding sources.

Goals

Virtually all of the programs (96%), according to their administrators, are directed at preventing institutionalization by making it possible to keep people in their own homes or communities. Two-thirds of the administrators state that containing the cost of long term care is also an objective of their programs. Only 16 programs (10%) are aimed at allowing people to work, or emphasize work as a goal, while still providing a personal assistance service subsidy.

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[12] Three administrators refused to cooperate; three questionnaires arrived too late to be counted, and 13 programs were not included because the State Area Agency on Aging had no overall statewide data on the Title III services in their states. Four programs, the Home Health Agency Programs in Alaska and Massachusetts, and the Chore Program and Homemaker programs in Massachusetts, were interviewed but were subsequently dropped from the survey results because they did not seem to be programs that offered long-term services. There may be others we should not have included, most likely a few of the purely "personal care" programs, but we decided to rely on administrator judgment unless the program was obviously delivering only acute health care and nursing services. Readers should note that, because administrators could not always answer every question, the number of programs responding to a particular question is noted in the tables where appropriate.

TABLE 1

NUMBER OF PROGRAMS BY STATE

State	# of Programs in Sample	# of Programs not in Sample	Total
Alabama	3	1[b]	4
Alaska	3		3
Arizona	1		1
Arkansas	2		2
California	4		4
Colorado	3	1[c]	4
Connecticut	5		5
Delaware	2		2
Florida	5		5
Georgia	1	2[b,c]	3
Hawaii	3		3
Idaho	3		3
Illinois	2		2
Indiana	4		4
Iowa	2		2
Kansas	4		4
Kentucky	3	1[b]	4
Louisiana	0	1[b]	1
Maine	5		5
Maryland	3	2[b]	5
Massachusetts	6		6
Michigan	3		3
Minnesota	2	1[a]	3
Mississippi	2		2
Missouri	6		6
Montana	4		4
Nebraska	3	1[b]	4
Nevada	4		4

State	# of Programs in Sample	# of Programs not in Sample	Total
New Hampshire	4		4
New Jersey	3	1[b]	4
New Mexico	5		5
New York	6		6
North Carolina	2	2[a]	4
North Dakota	1		1
Ohio	6		6
Oklahoma	2	1[b]	3
Oregon	2		2
Pennsylvania	3		3
Rhode Island	4		4
South Carolina	2	1[b]	3
South Dakota	3		3
Tennessee	1		1
Texas	4		4
Utah	3		3
Vermont	2		2
Virginia	2	1[b]	3
Washington	2		2
West Virginia	1	1[c]	2
Wisconsin	5		5
Wyoming	1	1[a]	2
Dist.of Columbia	2	1[b]	3
TOTAL	154	19	173

[a] Refusals: Minnesota Waiver Program and North Carolina and Wyoming Title XX Programs

[b] Title III Programs for which state agency on Aging had no state-wide data

[c] Waivers: Questionnaires arrived too late to be included in data set.

Number Per State

On the average there are three programs per state. The range is from one program each in Arizona, Louisiana, North Dakota and Tennessee, to six each in Massachusetts, Missouri, New York, and Ohio, with the most frequent number of programs per state being two. It is encouraging to note that there is no state without a personal assistance service program of some sort, which means there is a basis upon which to build and demonstrate the extent of need in any particular state. This does not mean, however, that anywhere near all the people who need services are being served.

Year of Implementation

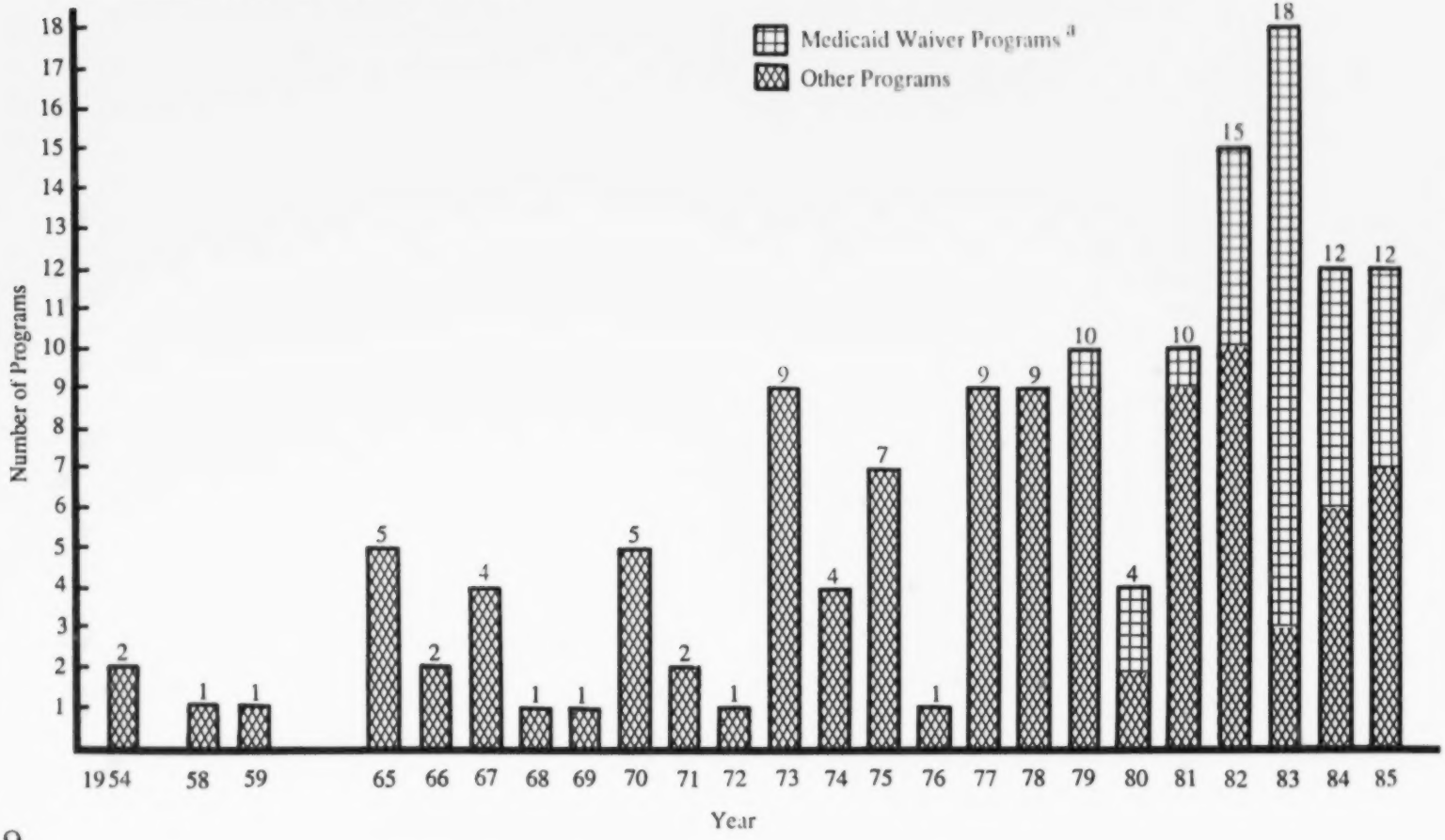
The programs range in age from 32 years old to less than one year old (Fig. 1). Only four programs were in existence before Titles XVIII (Medicare) and XIX (Medicaid) of the Social Security Act were enacted. The four programs established prior to 1965 were the Connecticut Essential Services Program (1954), the Montana Home Attendant Program (1954), the In-Home Supportive Service Program in California (1959) and Washington, D.C.'s In-Home Support Services Program (1958).

After the establishment of Medicaid and Medicare, the number of programs grew slowly. The rate of increase rose after the Title XX (Social Services Block Grant) was enacted in 1974 and remained at a fairly steady rate of increase until the 1980's. Eighty programs (56%) started after 1980, among them the 37 Medicaid Waiver Programs for physically disabled children and adults of all ages authorized as a result of the Omnibus Budget Reconciliation Act of 1981. As noted earlier, the federal

government greatly decreased the number of Waiver approvals beginning in 1985, and it is likely that the number of new federal programs being initiated will continue to be sharply reduced unless there is a change in federal policy.

Figure 1

NUMBER OF ATTENDANT SERVICE PROGRAMS IMPLEMENTED BY YEAR (n=145)



[a] One waiver program administrator did not know the date the program was implemented. One waiver program was established in 1970 and received a waiver in 1981. It is included among the five programs established in 1970. Waiver programs exclusively for people with mental and intellectual disabilities are not included.

Administering Agencies

The bulk of programs (45%) are administered by the state level agencies (often called Departments of Social Services, Human Resources or Public Welfare) which have jurisdiction over social, health and welfare programs. As can be seen in Figure 2, 27% of the programs are administered by the State Agencies on Aging directly; 17% are administered by either medical assistance or health departments. State vocational rehabilitation agencies administer only 7% of the programs using funds from state sources, not federal vocational rehabilitation allocations. An unexpected finding is that the personal assistance services programs in Maine, Nevada, North Carolina, and South Dakota are administered directly by an Independent Living Program.

Figure2

TYPES OF ADMINISTERING AGENCIES (n=147)

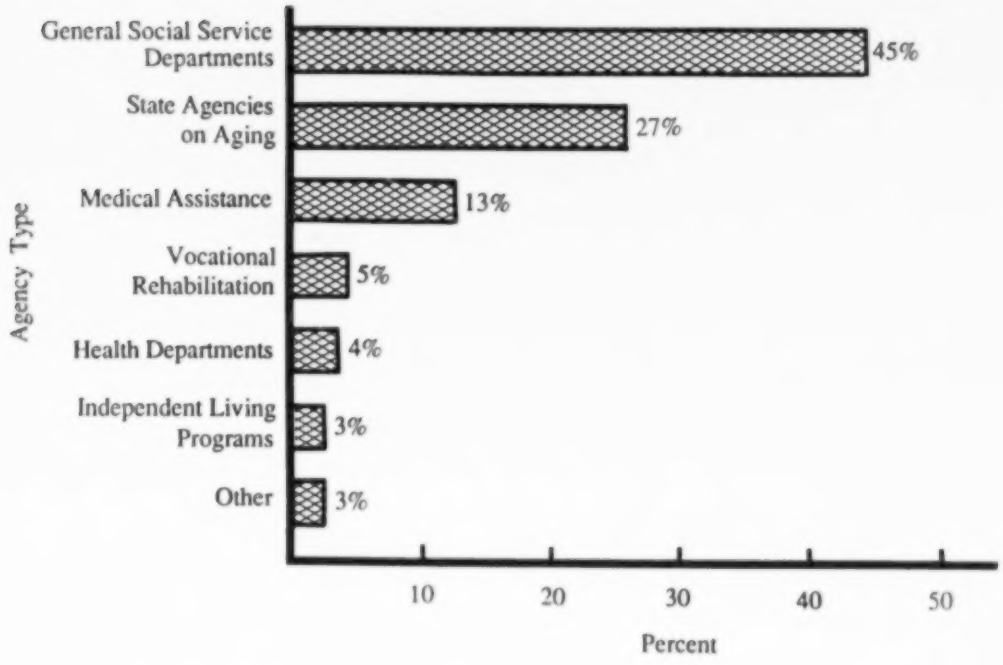


Figure 2

Funding Sources

More than a third of the programs rely on Medicaid funds, including expenditures under Medicaid Waivers granted by the Health Care Financing Administration of the U.S. Department of Health and Human Services (Table 2). As explained above, state Medicaid programs combine federal, state and (in some states) local funds. Somewhat less than a quarter of the personal assistance programs are funded by Social Services Block Grants, Title XX of the Social Security Act. Twenty-two percent of the programs are funded entirely from state or local sources. Allocations from Title III of the Older Americans Act are the sole federal funding source for 10% of the personal assistance programs. Only 12 programs (8%) function on a combination of federal funding sources. The respondent for one program administered by an Independent Living Program reported that funds from Title VIIB of the Rehabilitation Act were used when the personal assistance program was first established, which was the year included in the survey.

TABLE 2

PERCENTAGE OF PERSONAL ASSISTANCE PROGRAMS
FUNDED BY VARIOUS SOURCES (n=141)

Funding Source	Programs Number[a]	Percent
Title XIX:	51	36%
Title XX (SSBG)	32	22%
State/Local	30	22%
Title III	15	10%
Mixed Federal:		
Titles XIX & XX	6	4%
Titles XIX, XX & III	2	1%
Titles XX & III	3	2%
Titles XIX & III	1	.6%
Title VIIB	1	.6%

[a] There were 13 program administrators who were unable to specify the source of funding.

CHAPTER IV

PROGRAM STRUCTURE

This chapter provides a broad overview of the structure of the programs surveyed, including eligibility criteria, types and extent of services available, who actually provides the services, and who evaluates the user to determine service need. No attempt was made to judge the quality of the services provided.

Eligibility

Programs determine eligibility based on a large number of factors including age, employment status, disability type, and degree of poverty.

Age Range

Most of the programs (88%) will serve people over 60 or 65 years old. Somewhat fewer (72%) serve adults between the ages of 18 and 64. Less than half (45%) serve children. Although some administrators questioned whether programs can successfully serve people of all ages given their different needs, many programs do just that. Currently 41% of the programs serve people of all ages while 26% combine adults of all ages or children with adults under age 65 (Table 3).

TABLE 3

AGE RANGES ELIGIBLE BY PROGRAMS (n=153)

Age Range	Programs Number	Percent
All ages	62	42%
18 and above	38	24%
65 and above	36	23%
18 - 64	9	6%
Less than 18	6	4%
Less than 65	2	1%

Disability Groups Served

In terms of disability groups served, 58% of the program administrators say they serve people with all types of disabilities, physical (including those with brain injuries), intellectual and emotional. 26% of the programs serve only people with physical disabilities and those with brain injuries; and another 10% serve only those with physical disabilities (Table 4).

The fact that so many programs accept people with emotional and intellectual as well as physical disabilities calls into question the hypothesis that the service system for people with these disabilities tends to be quite separate. It also raises the question of whether separate personal assistance programs for people with emotional and intellectual disabilities with costly separate administrations are really necessary. It would be most interesting to explore the additional personal assistance service programs administered through State Departments of Developmental Disabilities and Mental Health to determine how many of them there are and how they differ from the programs in this survey.

TABLE 4

DISABILITIES OF INDIVIDUALS
ELIGIBLE TO BE SERVED(n=136)

Disability	Programs Number	Percent
Physical Disability, Brain Injury, Intellectual Disability, Emotional Disability	80	59%
Physical Disability, Brain Injury	35	26%
Physical Disability	14	10%
Physical Disability, Brain Injury, Emotional Disability	5	4%
Physical Disability, Brain Injury, Intellectual Disability	2	2%

Employment Status

As noted earlier, only 16 out of the 154 programs interviewed encourage people to work (Table 5). In fact, six of these require an individual to be employed in order to be accepted for the program, and 4 of these programs require, in addition, that people be employed a minimum of 20 hours per week.

TABLE 5

PROGRAMS HAVING THE GOAL OF ENCOURAGING PEOPLE TO WORK[a]

Name
Massachusetts Personal Care Program
Connecticut Personal Care Assistance Program
Maine (Attendant Program for Employed People)
Washington State Chore Services
Pennsylvania Attendant Care Demonstration
Nebraska Disabled Persons & Family Support Program
Nevada Attendant Care Program
Mississippi Independent Living Attendant Care Pilot Program
Alaska General Relief Medical Exception Program[b]
Maryland Attendant Care Program
Massachusetts Medical Assistance Program (for Hearing Impaired)
North Carolina Attendant Care Program
Ohio Personal Care Assistance Program
South Dakota Attendant Care Program
Utah Personal Attendant Care Program[b]
Vermont Personal Services Program

[a]Two other program administrators said their program had work as a goal but one served only SSI eligibles and the other was a Title III program.
[b]Program no longer exists

Income

Most of the programs not only do not encourage people to work, they require people to be poor (Figure 3). In 1985, the poverty level for a single person was $5,250 (US Department of Health and Human Services, 1985). Only 23% (35) of the 154 programs surveyed accepted people with incomes above $10,500, twice the poverty level. Half (77) of the programs either had specific limits of $5,250 or less, or limited eligibility to recipients of entitlement programs (such as Supplemental Security Income, Medicaid, or Social Security Disability Insurance) whose

Figure 3
INCOME ELIGIBILITY FOR SINGLE PERSONS
BY NUMBER OF PROGRAMS (n=93)

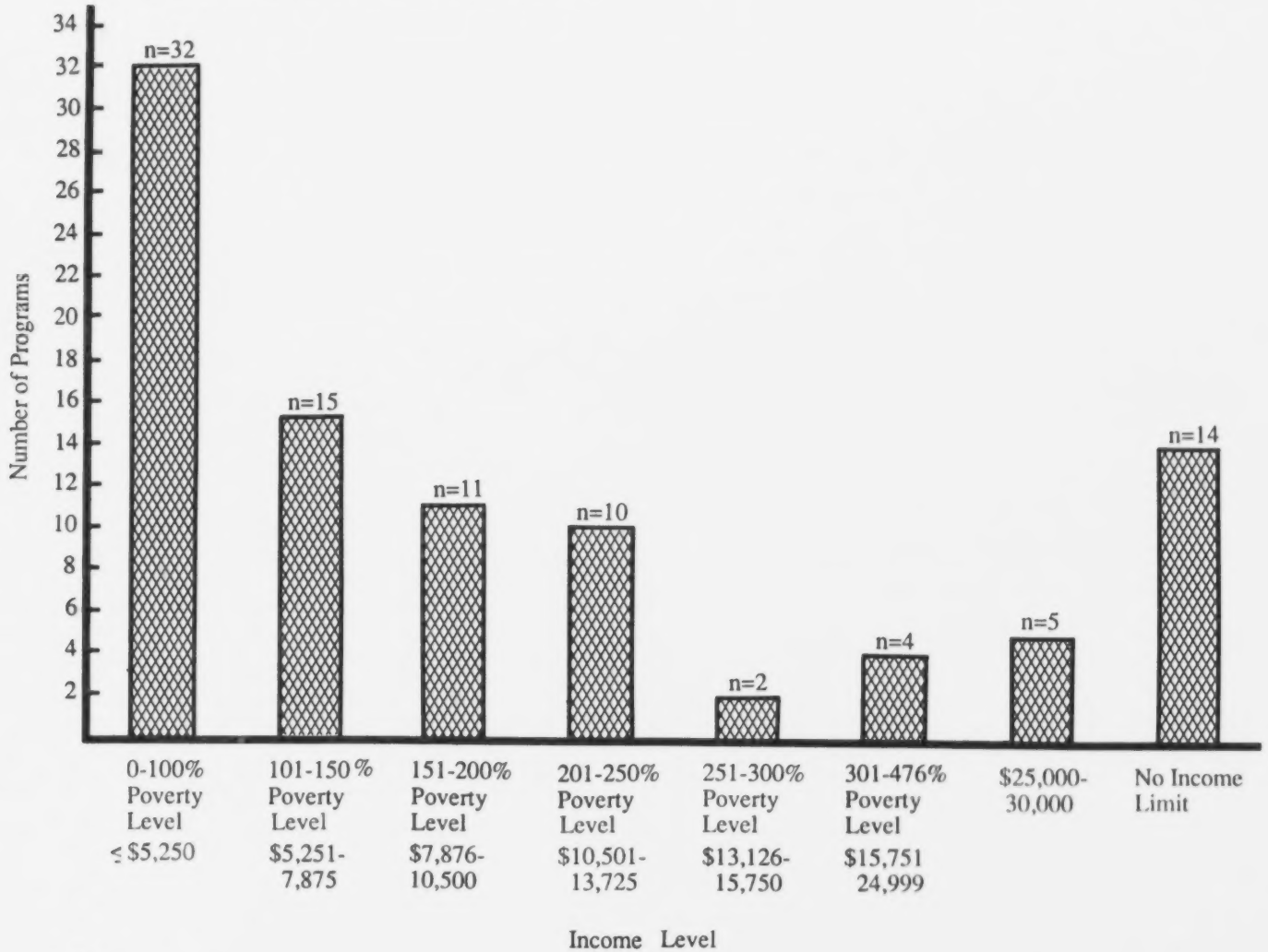


Figure 3

own income eligibility limits are near or below the poverty level.[13] Though there is no definitive study of the extra costs disabled people have to bear because of their disabilities, such as equipment replacement and repair, housing and clothing adaptation, medical insurance (if they can get it), and transportation, it is safe to assume that people with extensive disabilities earning less than $25,000 a year could not easily cover those expenses and the cost of an attendant for 20 or more hours a week.

Only 56 programs (36%) had a graduated shared cost formula, i.e., a system by which disabled individuals pay more and more of the cost of their personal assistant based on income up to a certain ceiling. The most adequate of these exclude disability-related expenses from income or have an income ceiling over $20,000 per year (e.g. programs in Maryland, Pennsylvania, Ohio, South Dakota and Vermont.) Without such a system, the most severely disabled with high disability costs would have to earn very high incomes in order to afford an attendant, apartment, transportation, medical bills and the like on their own.

Other Eligibility Criteria

In addition to age, disability type, employment status and income level, the programs surveyed had a wide variety of other eligibility requirements which are listed below in Table 6. The two most common were being at risk of institutionalization (57%) and physician's orders (42%). There were some programs that only admitted people who lived in certain counties or cities within a

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[13] See Methodology, Appendix B, for operational definitions.

state. Some of these were Medicaid Waiver or demonstration projects, but others, like the programs in Nevada which are locally funded and administered and are limited geographically to the two urban areas around Reno and Las Vegas, are permanent programs. Most unusual were programs that only accept people with very narrowly specified disabilities, eg. traumatic spinal cord injuries, or a certain level of functions, eg. wheelchair user or inability to use a certain number of limbs. Some programs which only use individual providers supervised by the recipient require recipients to be able to manage their own attendants.

TABLE 6

PARTIAL LIST OF ELIGIBILITY REQUIREMENTS(n=154)

Requirement	Programs Number	Percent
Risk of Institutionalization	89	57%
Physician's Orders	65	42%
Family Unable/Unwilling to provide Attendant Services	34	22%
Severe Disability	26	17%
Resident in Certain Geographic Area	25	16%
Able to Manage Own Attendant	21	13%
Inability to use certain number of limbs[a]	11	7%
Currently a Nursing Home Resident	7	5%
Wheelchair User	5	3%
Member of Specific Disability Group	5	3%
Living Alone	5	3%

[a] two limbs (n=4); three limbs (n=3); four limbs (n=4)

Services

The survey (See Appendix C) divided the possible services into personal, domestic and related services. Personal services are those which involve bodily contact. As one can see in Figure 4, there are a certain core of services - such as dressing, bathing, oral hygiene and grooming - that were offered by almost every program in the sample. Even programs that offer mainly "homemaker" and "chore" services tend to offer dressing, limited hygiene and feeding. Far fewer programs allow assistants to help with catheter management or to administer injections and medications.

Domestic services are as important to an attendant program as personal services. Domestic services involve tasks necessary to maintain one's home. As can be seen in Figure 5, most programs offered meal preparation, light cleaning, meal clean-up, laundry and shopping. Less frequently available are the heavier and more infrequent tasks which are also an important part of maintaining one's home.

In addition to personal and domestic services, there are a number of related services that are often necessary to sustaining a disabled individual at home on a long term basis. Figure 6 lists the percentage of programs offering some of these additional services. Transportation offered by these programs is most often for medically related outings. Escort is sometimes available for general shopping as well. However, consumers who manage their own assistants can use them for a wider variety of trips.

Figure 4

PERCENTAGE OF PROGRAMS OFFERING VARIOUS TYPES OF PERSONAL MAINTENANCE/HYGIENE SERVICES (n=154)

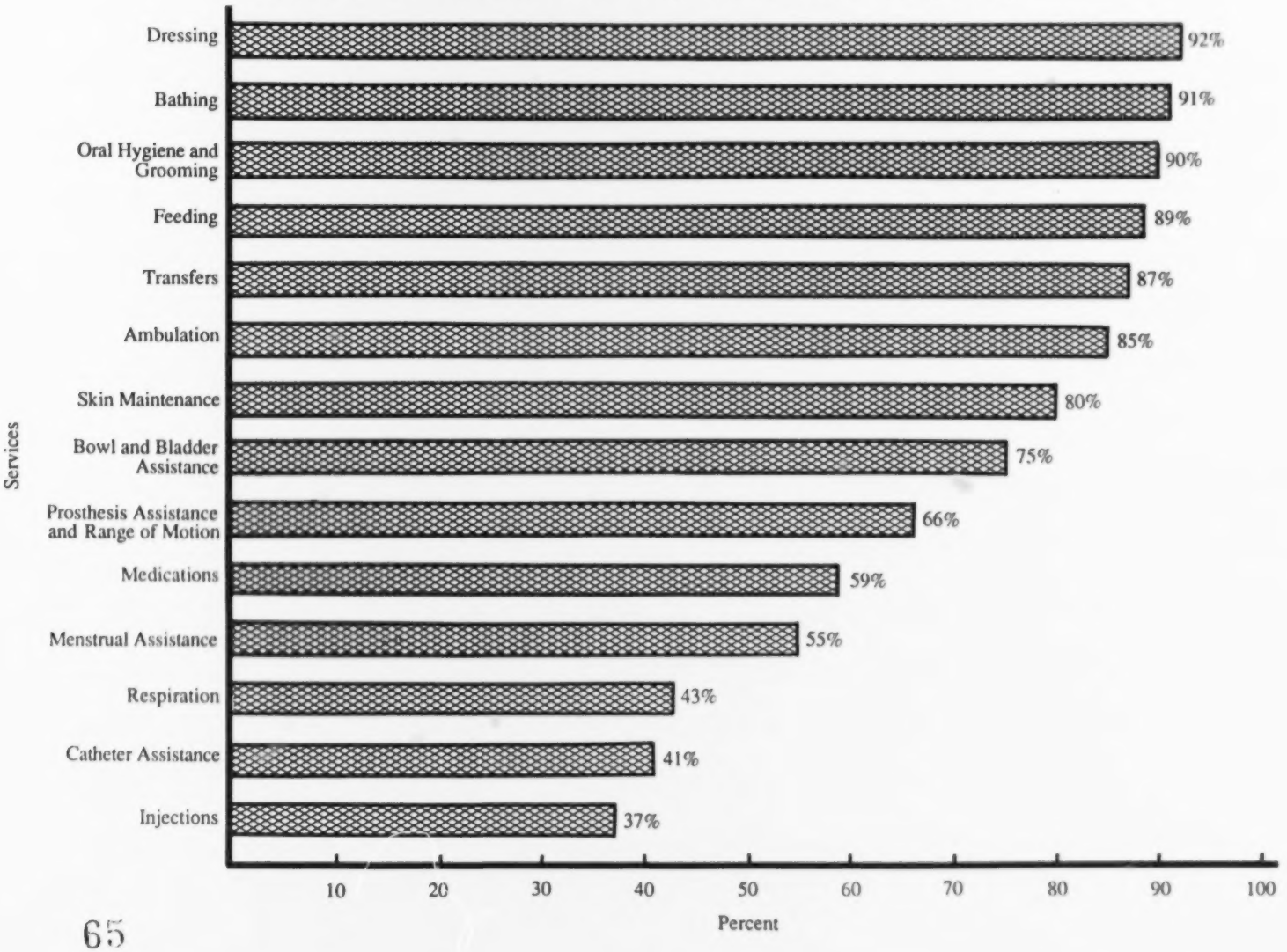

Figure 4

Figure 5

PERCENTAGE OF PROGRAMS OFFERING VARIOUS TYPES OF HOUSEHOLD ASSISTANCE SERVICES (n=154)

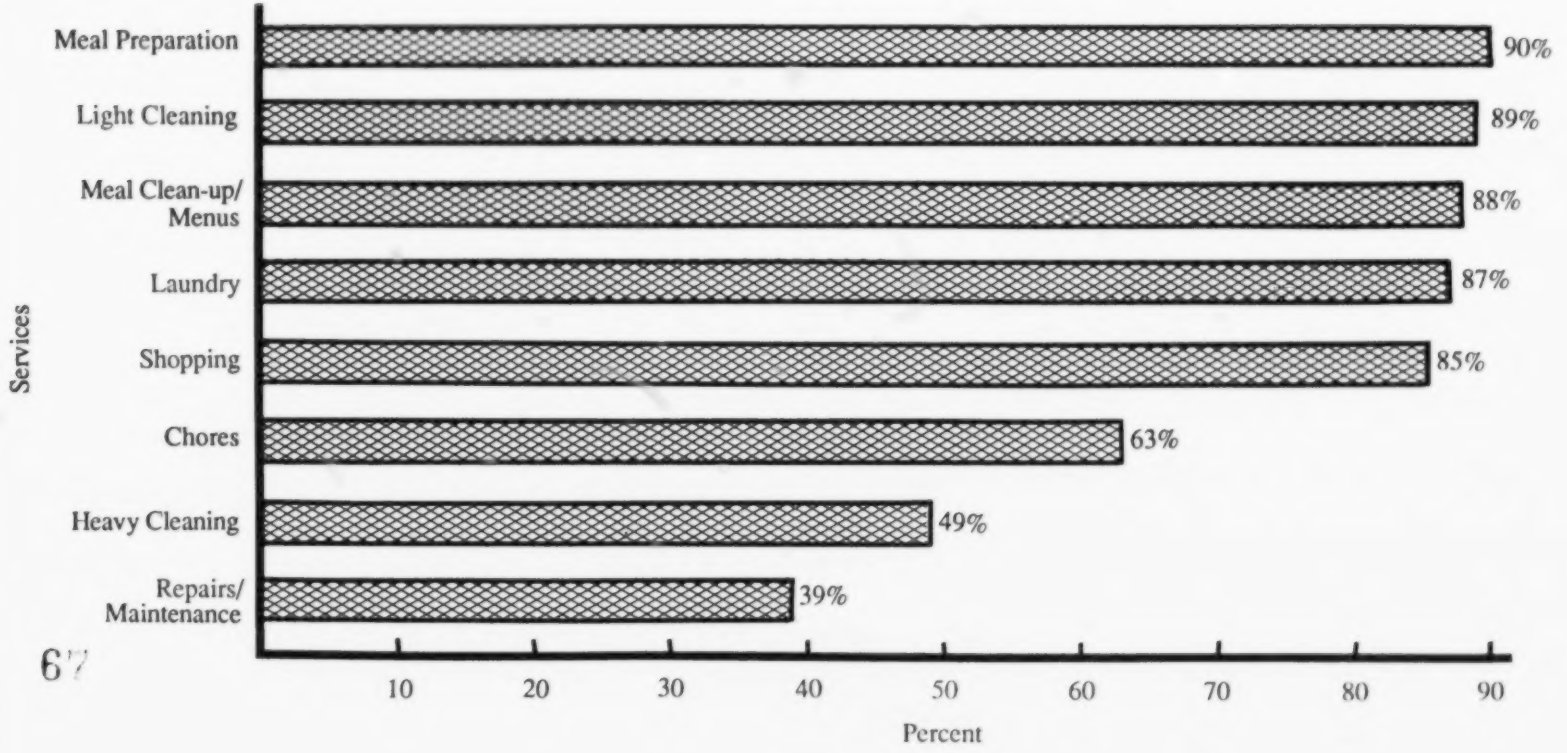

Figure 6

PERCENTAGE OF PROGRAMS OFFERING
VARIOUS TYPES OF RELATED SERVICES
(n=154)

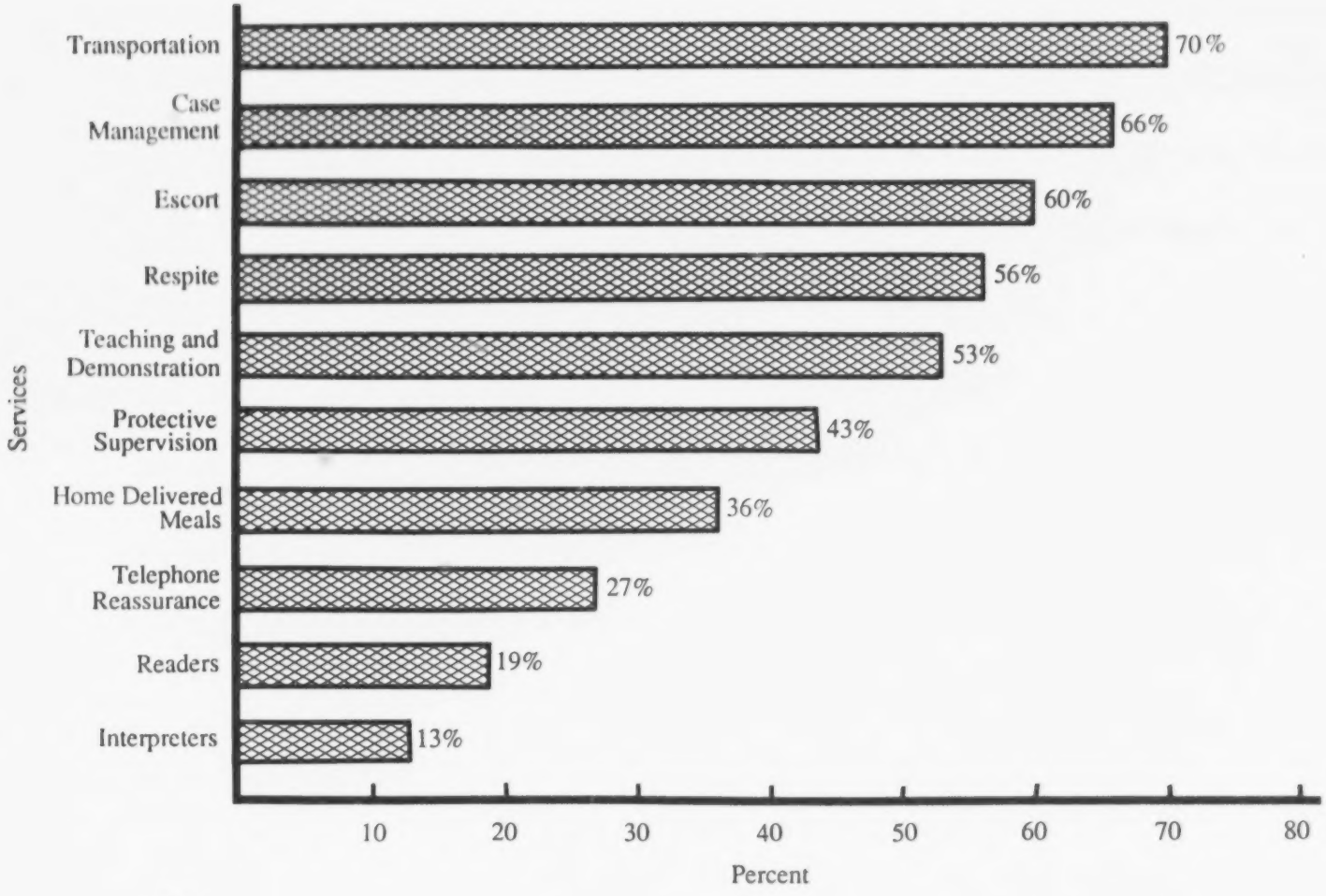

Figure 6

It was heartening to learn that more than half the programs in the country included some sort of short-term (respite) services. Respondents did not specify the extent of these services, so it is not possible to say how many only offered services for a few hours at a time rather than for 24 hours a day for a week or more.

Very few programs offered readers for those with visual disabilities or interpreters for people with hearing or speech disabilities. Few realize the major expense these services can be for disabled people nor how important they are to fostering independence and ability to work and participate in one's community.

In addition, there are a number of services and aspects of service delivery which merit further study. First is the issue of child care. Currently, California is attempting to prohibit people with disabilities from using their assistants to care for children. As more and more people with disabilities choose to have children, this issue should become very controversial. Second are emergency services, which are essential to people living on their own. Back-ups are needed if an assistant cannot work. Some ILP's maintain pools of people available for emergencies, but this service needs to be widely available.

Other services not covered in the survey are adult day services, transportation programs not associated with personal assistance service programs, and cognitive services for people with intellectual disabilities. We also did not inquire about the degree of geographic mobility that programs allow. Can personal assistants accompany the consumer to work, out-of-town,

to recreational activities, and so on? Obviously the more control a consumer has over the assistant's duties, the more such outings can occur. However, limits on the amount of service allowed will circumscribe the extent to which a consumer can utilize an assistant for long periods away from the home. The availability of personal assistance services outside the home is a major factor in the integration of people with extensive disabilities into society.

In order to get a clearer picture of the configuration of services offered by personal assistance programs across the U.S., a core of services was judged to define a certain type of service. The core of personal services is feeding, bathing, dressing, bowel and bladder care, oral hygiene and grooming, and transfers. It seemed to the WID staff that these services are the basic minimum of personal services. In addition, it is our opinion that programs need to provide catheter management in order adequately to serve disabled people. The core of domestic services is light cleaning, laundry, shopping, and meal preparation and clean-up. The combination of these domestic and personal services we consider to be a basic attendant service program.

As shown in Table 7, 90 programs (58%) provide both personal and domestic services, but 39 of these otherwise comprehensive programs do not offer catheterization and thus cannot meet the needs of those disabled people who need this service. Twelve percent of the programs only provide personal services and 25% offer domestic services only. In some states, the only way disabled individuals can get the range of attendant services they

need is by arranging services through separate programs. Eight programs (5%) provide short-term services (respite) only. In Wisconsin, for example, there is one program, the Respite Care Project, that provides short-term personal assistance for people of all ages all over the state.

TABLE 7

NUMBER AND TYPES OF PROGRAMS IN SAMPLE (n=154)

Program Type	Program Number	Percent
Attendant with Catheterization[a]	51	33%
Attendant without Catheterization	39	25%
Personal Service Only with Catheterization[b]	11	7%
Personal Service Only without Catheterization	7	5%
Domestic Services Only[c]	39	25%
Short-Term (Respite) Only[d]	8	5%

[a]Attendant = Personal Service[b] + Domestic Services[c]
[b]Personal Service = Feeding, ~~Ba~~thing, Dressing, Bowel/Bladder Care, Transfers, Oral Hygiene and Grooming
[c]Domestic Services = Light Cleaning, Laundry, Shopping, Meal Preparation and Clean-Up
[d]Respite = Provision of relief for usual service provider (family, attendant, friends) for periods from 1 hour to a number of days or weeks

Hours Services Available

A program may offer a very wide range of services that meet the assistance requirements of people with even the most severe disabilities, but if the disabled recipient cannot receive those services when they are needed, the program is inadequate.

Program rules often require that providers be employees of home health agencies. Often these agencies provide services only from 9-5, Monday through Friday. This is a fine schedule from the point of view of an employee, but from the point of view of disabled consumers it is almost totally inadequate. The periods of greatest personal assistance need are when one gets up in the morning (in time to get to work or other activities) and when one goes to bed at night (after one has had an evening of recreation or other activities). More domestic services do, of course, fit into a 9-5 weekday schedule. It is not unheard of for attendant service users to be forced to go to bed at 5 p.m. because attendants do not work after that time.

Only 65% of the programs make personal assistance services available 24 hours a day (Table 8). If one adds to this those programs that offer services less than 24 hours a day (but more than 9-5), then 76% of the programs potentially offer services at the necessary times. However, this finding must be viewed cautiously because often programs weren't strictly 9-5 operations but the hours were only somewhat broader, eg. 8:00 - 7:30. In addition, many administrators did not know the hours of service in every section of the state and tended to give an answer describing the general trend. In many states, however, the hours are determined by the contract agency and, in less populous areas, where home care agencies have no competition, the tendency is to restrict hours of service.

TABLE 8

HOURS SERVICE AVAILABLE (n=152)

Hours	Programs Number	Percent
24 hours/day	101	65%
Less than 24 hours/day (but not strictly 9-5)	32	21%
Strictly 9-5	19	12%

TABLE 9

DAYS SERVICE AVAILABLE (n=153)

Days	Programs Number	Percent
Every day	120	77%
Less than every day, more than only weekdays	9	6%
Weekdays only	24	16%

TABLE 10

HOURS AND DAYS OF SERVICE AVAILABILITY (n=143)

Hours and Days	Programs Number	Percent
7 days/week, 24 hours/day	101	66%
7 days/week, but less than 24 hours/day	18	12%
Less than 7 days/week, and less than 24 hours/day	24	16%

Fully 77% of the programs offer service every day (Table 9). If one combines hours and days of service, 66% of the programs have service available every hour of every day (Table 10). An additional 12% have services available every day on more than a 9-5 basis.

Maximum Service Amounts Allowed

There are two ways in which programs expressed the maximum service amounts allowed, either in hours or in terms of a maximum financial allowance. Fifty-four programs expressed the limit in monetary terms which ranged from $60 a month to $1,752. Fifty percent of these programs had allowances of less than $838, fifty percent had limits above that. An additional 44 programs set no maximum monthly allowance, either in terms of hours or money. There were 38 programs that give the maximum allowance in terms of hours. The hours ranged from 3 to 67 per week, with an average of 29 hours.

In order to clarify the impact of the maximum allowance on the consumer, the monthly monetary allowance was divided by the average hourly wage for all types of attendants, $4.41, and further divided by 4 to get a weekly figure.[14] As Figure 7 shows, 18% of the programs have limits of 20 hours a week or less, and therefore may not serve the needs of an individual with a severe disability.

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[14] This figure tends to inflate the number of programs which provide more than 20 hours/week because the programs with the highest financial allowances generally allow for home health aide service provision. The average cost to the program for home health aides is almost twice the $4.41/hour average. See next section for more detail on provider wages.

Figure 7

MAXIMUM NUMBER OF SERVICE HOURS
ALLOWED PER WEEK (n=136)

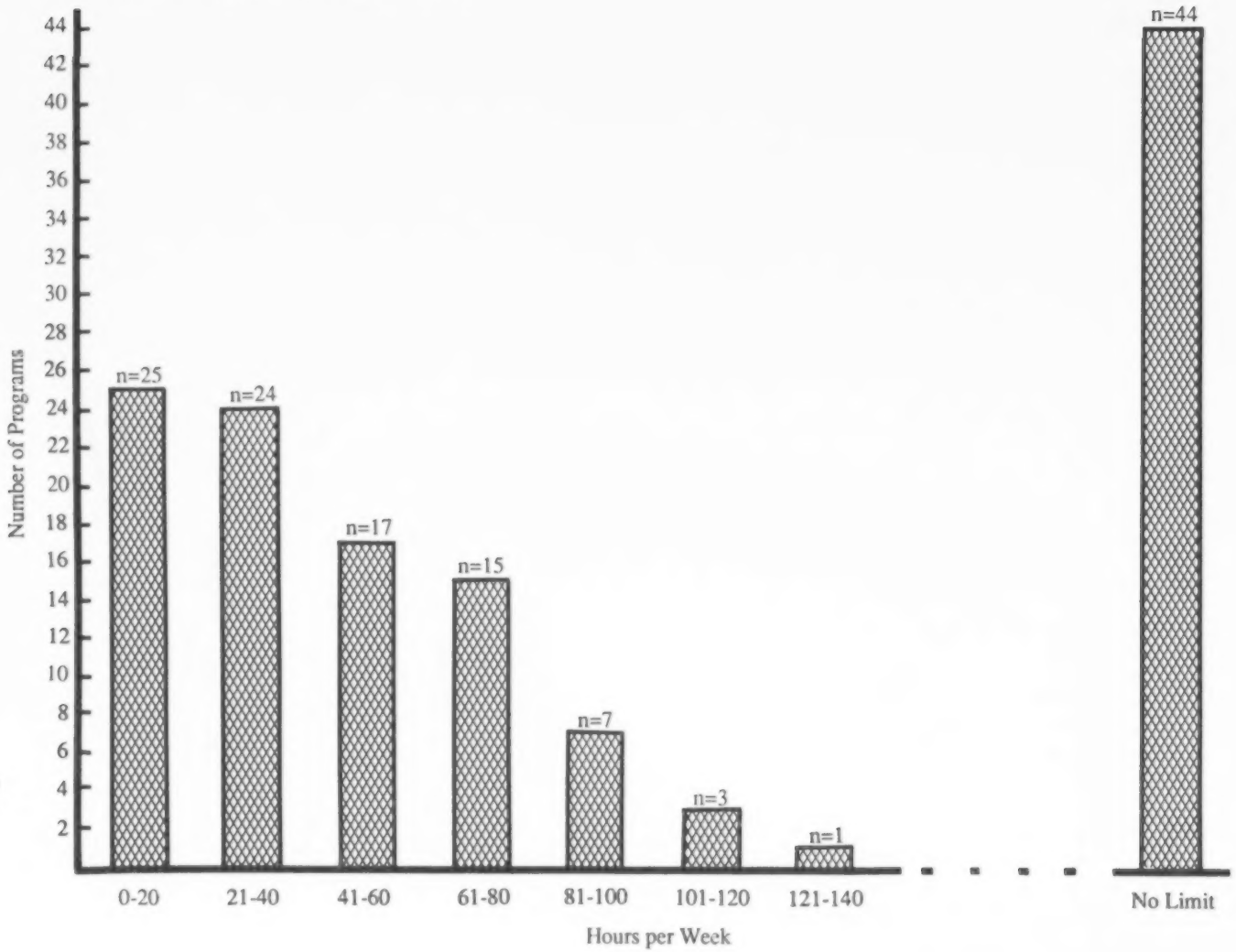

Figure 7

Direct Service Providers

The attendants could be divided into three groups, those who were individual providers (IPs), those who worked for contract agencies, and those who worked for county or municipal governments. The bulk of the programs (76%) utilized attendants provided by contract agencies. Fifty percent of the programs used individual providers and only 28% used government employees (Table 11). Many programs use more than one type of provider (Table 12). There are advantages and disadvantages to each type of provider. Consequently a program that offers service to a wide variety of people needs to provide a choice between individual providers and more agency trained and supervised contract or government workers.

TABLE 11

TYPES OF PROVIDERS UTILIZED BY PROGRAMS

Type	Programs Number	Percent
Contract Agencies	118	76%
Individual Providers (IPs)	77	50%
Local Government Unit Staff	44	28%

TABLE 12

PROVIDER TYPE MIX (n=154)

Type of Provider	Programs Number	Percent
Contract Agencies Only	54	35%
Individual Providers Only	33	21%
IPs and Contract Agencies	24	16%
IPs, Contract & Govt Staff	20	13%
Contract Agencies & Govt Staff	20	13%
Government Staff Only	3	2%

Individual Providers

Individual providers (IPs) are the preferred mode of service delivery for those who emphasize independent living and are able to manage their own personal assistants. Consumers have a far greater level of control of IPs. Sixty-two percent of the 77 programs utilizing IPs allow the consumer to train his or her own attendant, 74% allow the consumer to hire and fire their attendants, and a much smaller 40% allow direct payment to the disabled consumer who then pays his or her attendant.

Consumer control is a controversial issue because it raises the question of who is the employer, the governmental agency or the disabled individual. Many state administrators are concerned about the liability issue and the level of attendant training. Some are calling for certification of all attendants after completion of a formal training program. Consumers tend to oppose formal training and certification requirements because trained attendants often resist taking directions from the disabled client and - subtly or not so subtly - undermine independence. Only 64% of the programs using IPs require the disabled consumer to train the attendant (Table 13). In the survey we did not inquire whether programs required IPs to be licensed or certified in some way. While this seems to be an issue of growing concern, one should bear in mind that in the entire 27-year history of the California IHSS no one has ever sued the state for negligence related to an independent provider.[15]

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[15] See Zukas, H. (1986) for a fuller discussion of the liability issue.

TABLE 13

LEVEL OF TRAINING REQUIRED
FOR INDIVIDUAL PROVIDERS(n=77)

Type of Training	Programs Number	Percent
Trained by Client/Consumer	48	62%
Graduate of Agency Training Program	12	16%
Home Health Aide	5	6%
Licensed Practical Nurse	4	5%
Other	22	29%

Fifty-five out of 77 administrators questioned replied that their programs had regulations regarding IPs. In general the regulations were very minimal. They required such things as the individual must receive some sort of formal training (n=22) and/or be over 18 years old (n=27); others said that the regulations specify that the consumer must be able to supervise the attendant. Twenty-six percent of the programs said the only requirement is that the consumer request an individual provider. After that, the consumer is responsible for setting all limits.

Another controversial issue pertaining to individual providers is whether or not to allow relatives to be paid to be independent providers. Of the 77 programs that allow for IPs, 41 permit relatives to be paid providers under some circumstances. Table 14 lists the requirements regarding relatives that were mentioned by more than one administrator. Some programs seem to be somewhat flexible, depending on the situation. For example, relatives may be paid if the disabled individual needs specialized services that only family will or can provide or if the disabled individual lives in a remote area where no one is

available. Most of the other programs which have regulations regarding relatives seem to have guidelines based more on which relatives they think should be expected to provide services without pay and which should not - a rather arbitrary exercise as can be seen by the variety of different guidelines listed.

TABLE 14

CIRCUMSTANCES IN WHICH PROGRAMS ALLOW RELATIVES TO BE PAID ATTENDANTS (n=41)

Reason	Number	Percent
No one else is capable or available	13	31%
The relative is not legally responsible for the disabled individual	10	24%
Relative is prevented from working outside the home because no other attendant is available	9	22%
Relative does not reside in the same house	7	17%
Relative is not the spouse	7	17%
Any relative is okay	6	15%
No spouse, parent, child or son/daughter-in-law	4	10%
Niece, nephew, cousin okay	2	5%
No blood relatives or spouses	2	5%

Contract Agency Attendants

There are 118 programs which contract with outside agencies to provide personal assistants for their clients. Almost all of these programs contract with certified Home Health Agencies (n=102) and some (n=58) contracted with local government units also. Eighty-seven percent contracted with non-profit agencies

and 68% also contracted with for-profit agencies.

The average hourly reimbursement rate to the contract agencies was $8.32/hour with a range from a low of $3.50/hour to a high of $19.00/hour. Included in this range are wages for home health aides, chore workers and housekeepers. Every attempt was made not to exclude from these figures the reimbursement for allied health personnel such as registered nurses and the various types of therapists. The average hourly pay to the contract agency workers was $4.71/hour with a range from $3.00/hour to $10.00/hour. The average hourly difference between the reimbursement rate and the attendant's wages was $4.08 (range of 0-$14.38). This means that for those programs for which this information was available (n=52 or 44%), for every hour the attendant goes out, the contract agencies receive on the average $4.08 - almost a 100% mark-up.

Government Agency Attendants

Only 44 programs use attendants who are direct employees of the state or of local government units. One suspects that the number will further decline because current federal government policy greatly encourages private enterprise taking over service functions of government at all levels. Government workers earn, on the average, $4.77.

Comparison of Provider Types

In order to understand better the advantages and disadvantages of the types of providers, it is instructive to compare them on two dimensions, degree of consumer control allowed and attendant wages and benefits. Government workers

receive not only the highest wages but vastly more benefits, almost 5 apiece (Table 15). Wages for Contract Agency Workers were only slightly lower, on the average, but their benefit package is decidedly inferior. On the average, contract agency attendants get about 2 fringe benefits and they are most often social security and worker's compensation. Individual providers receive the lowest pay, very close to minimum wage, and very few, if any, benefits.[16]

TABLE 15

NUMBER OF BENEFITS AND AVERAGE HOURLY WAGE BY PROVIDER TYPE[a]

Provider Type	Average Hourly Wage	Benefits		
		Average Number	Benefits Range[a]	Mode
Government Workers (n=30)	$4.77	4.7	0-7	7
Contract Agency Workers (n=62)	$4.71	1.7	0-7	0
Individual Providers (n=60)	$3.74	.7	0-3	0

[a]Includes 1) vacation pay, 2) sick leave, 3) health insurance, 4) worker's compensation, 5) Social Security, 6) unemployment compensation and 7) transportation costs.

[16] The accuracy of these data is somewhat suspect because administrators tend not to be the people who know this information in detail. Even though they received questionnaires in advance, many did not take the time to check with people in their agencies who could accurately answer the wage/benefit questions. Nevertheless, we are confident results reflect the general trend. Government workers would be expected to receive the highest wages and benefits and individual providers would definitely receive the lowest.

In terms of consumer control, there are advantages and disadvantages to each type of provider depending on the user's circumstances. The degree of consumer control over the attendant is a major concern for the Independent Living Movement. Without control, the consumer is dependent upon the schedule, desires and agenda of the attendant - hardly a situation which fosters independence. Programs using IPs allow for the most consumer control (Table 16). Consequently, individual providers are a major attraction for independent living adherents. However, users of IPs must have the ability to manage their own attendants. Another drawback is that IP's tend to be paid at or very close to the minimum wage, receive very few, if any, benefits, and, as a consequence, have a very high turnover rate.

TABLE 16

NUMBER OF PROGRAMS ALLOWING CONSUMERS
TO TRAIN, PAY, AND HIRE AND FIRE ATTENDANTS

Type of Provider	Train		Hire/Fire		Pay	
	#	%	#	%	#	%
Individual Providers (n=77)	48	62%	57	74%	31	40%
Contract Agencies (n=118)	15	13%	5	4%	1	1%
Government Workers (n=44)	4	9%	4	9%	0	0%

Contract agency workers such as home health aides and homemakers tend to be paid somewhat better because they are trained by the agency or other training programs. Trained attendants are appropriate for disabled clients who are unable to manage totally their personal assistant. However, a client's independence can be undermined by a contract worker who takes too

much responsibility for what, when, where and how services get provided. Government employees, who tend to be utilized only when no private contract agency exists in an area, have the highest pay and benefits, but often they also discourage independence in the people they serve.

There are a number of important issues pertaining to who is the personal assistance service provider and the conditions of employment which need to be noted here. We did not inquire about unionization, but it is our impression that there are few unionized attendants in the U.S., except perhaps those who work for local or state governments.[17] Unionization would improve the working conditions and benefits for attendants.

This project did not explore the extent to which disabled people rely on unpaid providers such as family members and friends. That issue must wait for a consumer survey.

Determination of Services Allowed

We inquired as to who makes the decisions regarding types of services and hours that a consumer can receive from a program and the basis upon which those decisions are made. Functional ability and services needed are the primary indicators used for evaluating the client (Table 17).

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[17] In personal Communication with Kirk Adams, Senior International Organizer, Service Employees International Union, July 21, 1986, we learned that SEIU has organized 2,000 homemakers in Boston (out of a total of 15,000 in Massachusetts, 2,000 in Chicago, 500 in San Francisco and 20,000 state workers in New York City.

TABLE 17

BASIS FOR SERVICE EVALUATION

Criteria	Program Number	Percent
Services Needed	136	90%
Functional Ability	119	77%
Physician's Recommendation	83	53%
Accessibility of Environment	76	49%
Cost of Services Less Than Institutional Care	68	44%
Nursing Home Eligibility	31	20%

Service professionals, especially case managers, were found to be the primary decision makers as to hours and types of service to be provided. Users do not have much voice in these decisions (Table 18).

TABLE 18

THOSE WHO DECIDE ON TYPES OF SERVICE & HOURS
(n=154)

Decision Makers	Program Number	Percent
Case Manager	46	30%
Case Manager & Social Worker	15	10%
Program Director	18	12%
Social Worker	10	7%
User	9	6%
Registered Nurse with/ without Other Professional	8	5%
Contract Agency with/ without Case Manager	8	5%
Medical Assistance	6	5%
Independent Living Program	5	3%
Registered Nurse or Doctor	5	3%
User & ILP or Social Worker	2	1%
Other	22	14%

Medical Supervision

Nearly a quarter of the programs (n=37) require medical supervision by an R.N. or other health professional for all the program's services. A third of the programs (n=51) require medical supervision for some of the services, usually the more medically oriented ones, and 40% (n=61) of the programs require no medical supervision. Of those programs requiring supervision for some or all of the services, 34 (39%) require monthly supervision, 15 (17%) require bi-monthly supervision, 9 (10%) require quarterly supervision, and 12 (14%) require supervision from between every six months to once a year.

In this and the previous chapter we have taken a largely descriptive approach, breaking attendant services programs down into common structural and programmatic components and describing in turn how each of these components is addressed across the country. We will now shift our perspective and consider individual programs in their entirety in order to ascertain the degree to which they promote independent living.

CHAPTER V

PROGRAM CONFORMITY TO THE INDEPENDENT LIVING MODEL

DeJong and Wenker (1979), in their seminal work on personal assistance services, described the attendant programs in this country as lying on a continuum defined by the medical model on one end and the Independent Living Model on the other. The Medical Model can be seen most purely in programs aimed at serving people with acute conditions which require short term "care". In these programs a physician's plan of treatment is required along with periodic nursing supervision. Attendants are recruited, trained and supervised by the contract agency. The attendant is ultimately accountable to the physician and the recipient essentially plays the role of patient. Programs directed at people with short term "care" needs were not included in the WID survey. We did, however, include programs that served people with chronic conditions on a long term basis that operated very much on the terms described above.

The other end of the continuum DeJong describes is the Independent Living Model in which the attendant is managed by the user. No medical supervision is required. Attendants are recruited by the user, paid by the user and accountable to the user.

In order to see where the programs surveyed fit on the continuum, we gave each program a score from zero to ten based on a count of how many of the following ten characteristics of the pure Independent Living Model the program incorporated. These characteristics are:

1. No medical supervision is required;
2. The service provided is attendant service with catheterization, i.e. services offered include personal maintenance and hygiene, mobility and household assistance.
3. The maximum service limit exceeds 20 hours per week;
4. Service is available 24 hours a day, seven days a week;
5. The income limit is greater than 150% of the poverty level[18];
6. Individual Providers can be utilized by the consumer;
7. The consumer hires and fires the attendant;
8. The consumer pays the attendant;
9. The consumer trains the attendant.
10. The consumer participates in deciding on the number of hours and type of service he or she requires.

The bulk of the programs scored low on the degree of Independent Living orientation (Figure 8). However, as one might expect, the programs are indeed spread across the continuum. And there are in fact a few programs that do conform to the pure independent living type.

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[18] Actually setting the limit at more than 150% of the poverty level ($7,875) is generous. An income of $7,875 is very low to enable a single person to meet food, shelter, transportation and clothing costs and still be able to pay an attendant.

Figure 8

DEGREE TO WHICH PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=147)

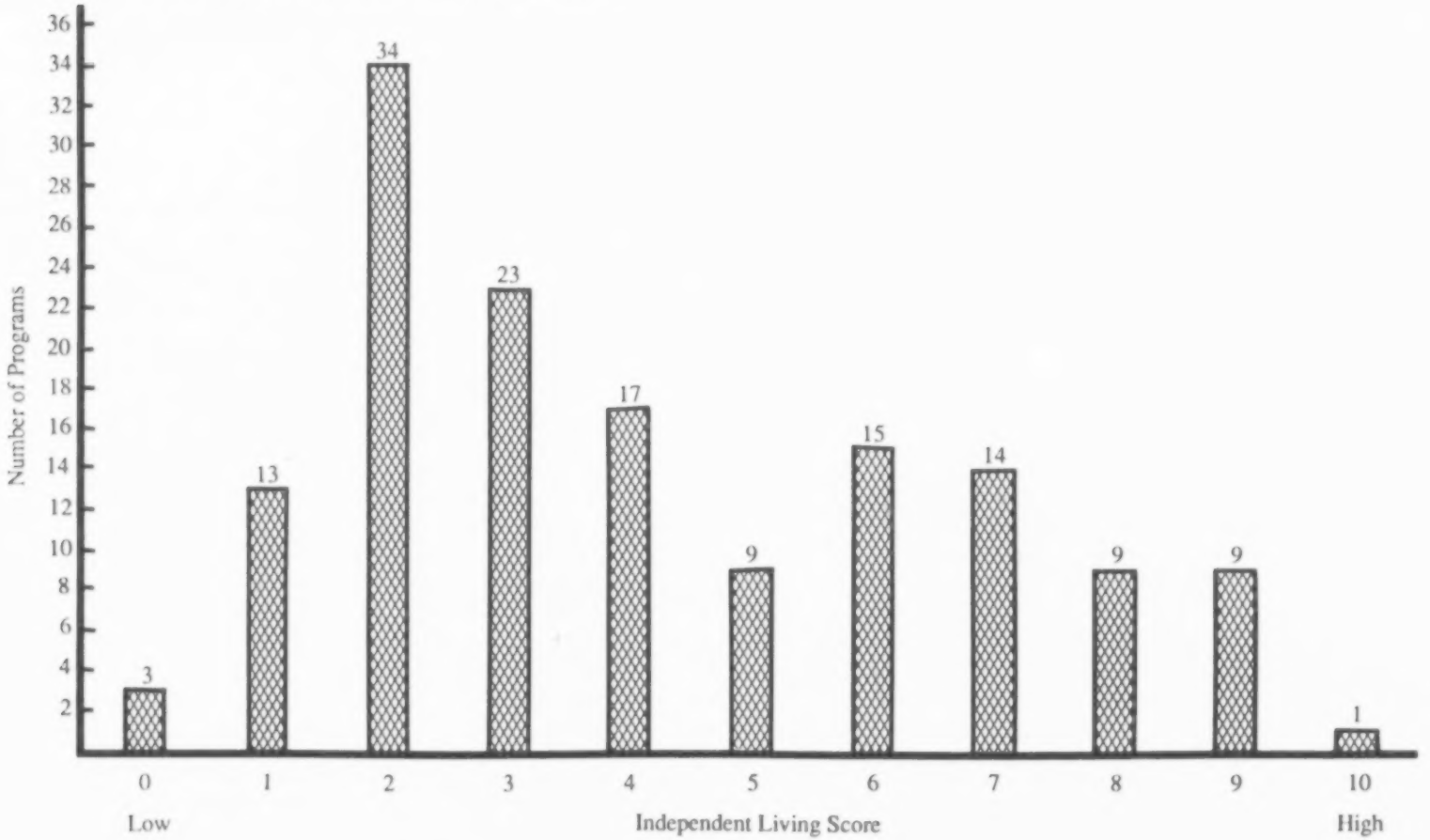

Figure 8

The programs that scored 0, 1, 2, or 3, the lowest independent living scores, served 385,445 clients or 49% of all those being served (Table 19). Fewer clients (210,436 or 27%) were served in the most independent living-type programs which scored 7, 8, 9, or 10 on the independent living scale.[19] And somewhat fewer (192,751 or 24%) were served by programs scoring in the middle range.

TABLE 19

NUMBER OF USERS SERVED BY ATTENDANT SERVICE PROGRAMS AT VARIOUS LEVELS OF CONFORMITY TO THE INDEPENDENT LIVING MODEL[a] (n=127)

Independent Living Score		Total Number of User	Number of Programs Reporting
Low	0	47,487	3
	1	87,719	11
	2	143,811	28
	3	106,428	19
	4	74,132	14
	5	64,195	9
	6	54,424	15
	7	172,984	14
	8	25,837	5
	9	11,065	8
High	10	550	1

[a]Does not include programs that only provide respite

[19] Note that California's IHSS program, which served 106,138 people in FY1984, is included among the programs scoring "7" on the Independent Living Model. The 550 users in the program with the highest score represent a projection, not the precise number served.

There seems to be a marked tendency for the expenditure per client to increase (but not necessarily per hour) as the programs become more consumer or independent living oriented (Table 20). This finding needs further exploration, however. It is quite likely that the more consumer oriented programs serve the most severely disabled people. Also, by definition, the independent living model programs provide the greatest number of hours of service because programs got an extra point for offering 20 or more hours of service per week on the independent living score.[20] Finally, the programs with the lowest independent living score are most likely to be those offering household assistance only.

TABLE 20

EXPENDITURE PER USER BY PROGRAMS AT VARIOUS LEVELS OF CONFORMITY TO THE INDEPENDENT LIVING MODEL (n=119)

Independent Living Score		Expenditure per User	Number of Programs Reporting
Low	0	$ 811	3
	1	570	11
	2	2,853	28
	3	1,916	16
	4	3,922	12
	5	4,622	9
	6	2,441	13
	7	3,729	13
	8	2,403	5
	9	3,079	8
High	10	7,636	1

[20] Cost per hour of service would have been a more desirable measure for comparison since it would have eliminated the need to take account of these variables. However, not enough programs were able to provide these figures for the current survey.

Figures 9, 10, 11 and 12 provide some evidence to support this explanation. The Social Services Block Grant and Medicaid-funded programs tend to have the lowest independent living or consumer orientation, whereas the state-funded programs have the highest.

Small states are more likely to have independent living-oriented programs than are large states (Table 21). Half of the states have programs that score 7 or better on the independent living orientation scale. These programs, their independent living model scores and the states where they are located are detailed in Table 22.

Figure 9
DEGREE TO WHICH TITLE XIX FUNDED PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=48)

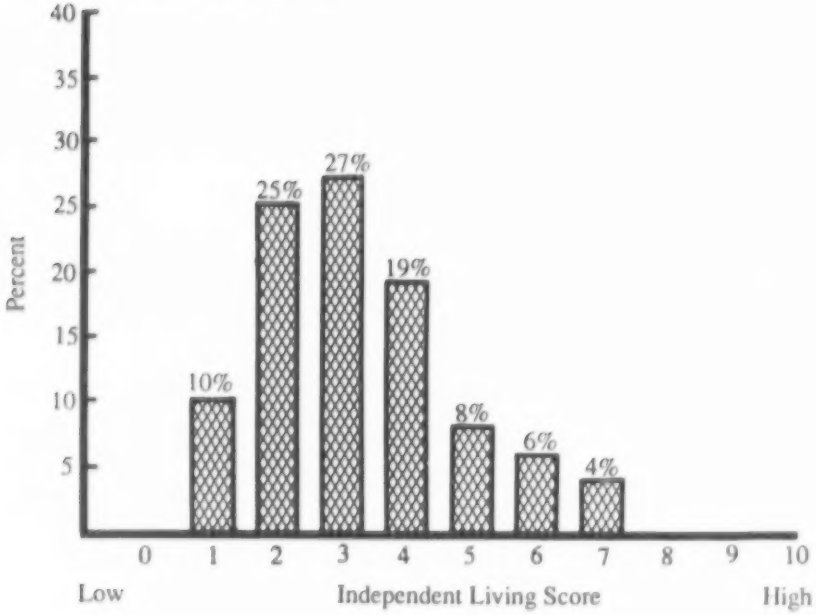

Figure 10
DEGREE TO WHICH TITLE III FUNDED PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=11)

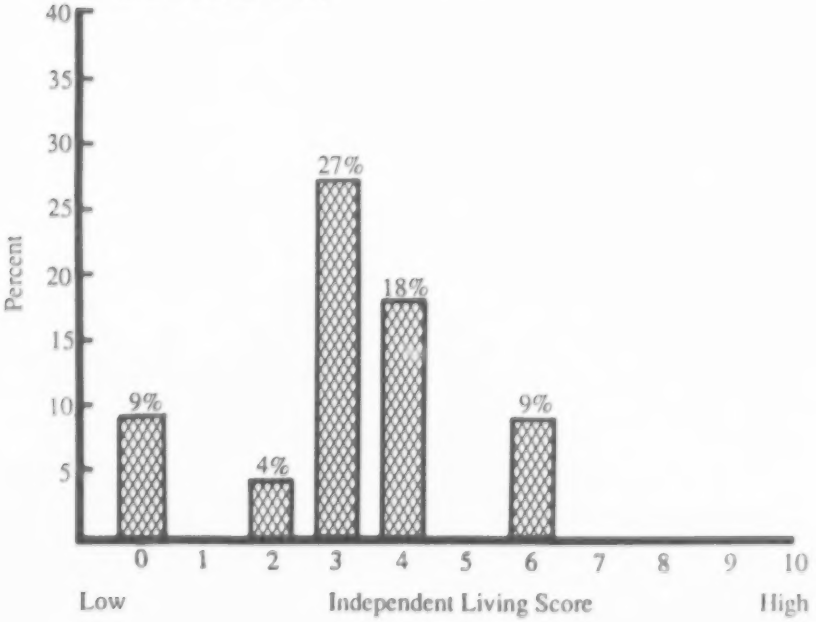

Figure 11
DEGREE TO WHICH SSBG FUNDED PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=29)

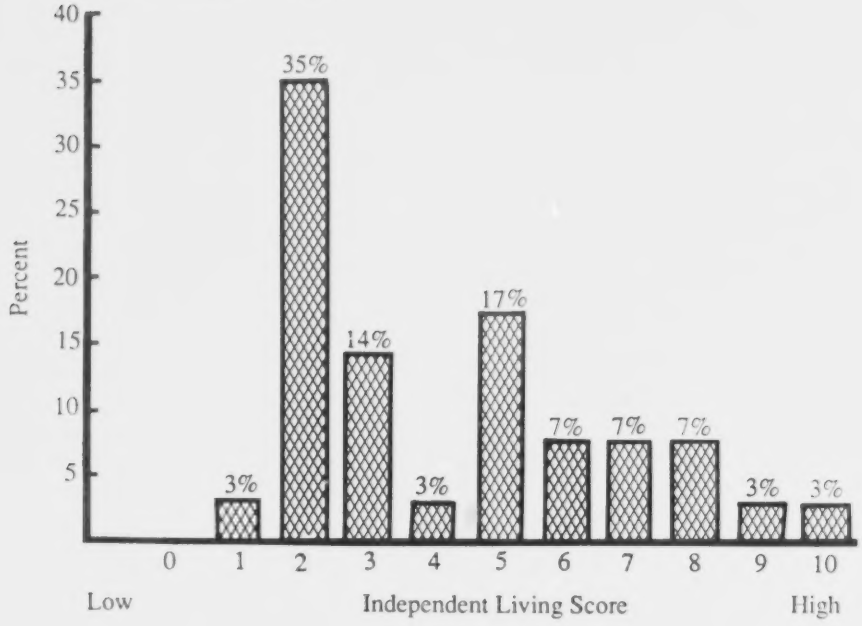

Figure 12
DEGREE TO WHICH TOTALLY STATE AND/OR LOCALLY FUNDED PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=16)

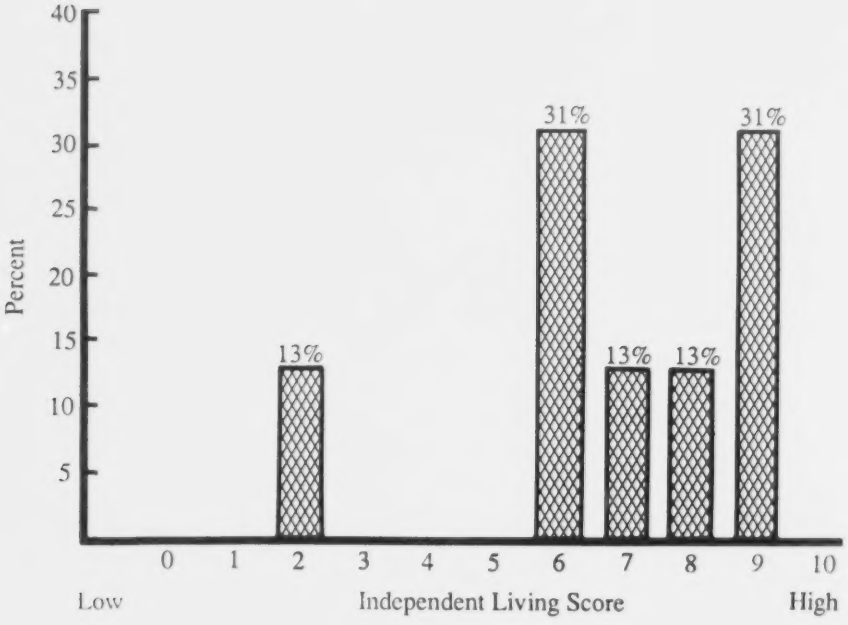

TABLE 21

DEGREE OF CONFORMITY TO INDEPENDENT LIVING MODEL BY STATE (n=147)

	Number of Programs by Degree of Conformity to Independent Living Model										
	Low										High
STATE	0	1	2	3	4	5	6	7	8	9	10
Alabama		1	1					1			
Alaska				1	2						
Arizona							1				
Arkansas		1						1			
California	1		1	1				1			
Colorado						1	1				
Connecticut		1	1				1	2			
Delaware				2							
Florida			3		1		1				
Georgia			1								
Hawaii		1		1			1				
Idaho			1	1		1					
Illinois								2			
Indiana			3		1						
Iowa		1					1				
Kansas			1	1		1	1				
Kentucky		1	1						1		
Louisiana											
Maine					1			1	1	2	
Maryland					1		1		1		
Massachusetts		2			1			2			
Michigan			1			1			1		
Minnesota						1					
Mississippi			1						1		
Missouri		2	1	2						1	
Montana			1	1	1						
Nebraska				1			1		1		
Nevada		1	2							1	

Number of Programs by Degree of Conformity to Independent Living Model

	Low										High
STATE	0	1	2	3	4	5	6	7	8	9	10
New Hampshire			1	2					1		
New Jersey			3								
New Mexico			1	2	1		1				
New York			1	1	2						
North Carolina					1			1			
North Dakota				1							
Ohio		1	1	1	1					1	
Oklahoma					2						
Oregon							1	1			
Pennsylvania				1					1		1
Rhode Island			2	1			1				
South Carolina			2								
South Dakota	1								1	1	
Tennessee		1									
Texas			1	2			1				
Utah	1			1						1	
Vermont						1				1	
Virginia			2								
Washington							1			1	
West Virginia						1					
Wisconsin			1			1	1	2			
Wyoming					1						
Dist.of Columbia					1	1					

TABLE 22

PROGRAMS WITH THE HIGHEST INDEPENDENT LIVING ORIENTATION

Rating	State	Program Name
10	Pennsylvania	Attendant Care Demonstration
9	Maine	Home and Community-Based Waiver
	Maine	Homebased Care Program
	Missouri	Personal Care Assistance Program
	Nevada	Attendant Care Program
	Ohio	Personal Care Assistance Program
	South Dakota	Attendant Care Program
	Utah	Personal Attendant Care
	Vermont	Participant Directed Attendant Care
	Washington	Chore Services
8	Kentucky	Personal Care Attendant Program
	Maine	Attendants for Employed People
	Maryland	Attendant Care Program
	Michigan	Home Help
	Mississippi	Independent Living Attendant Care Pilot Program
	Nebraska	Disabled Persons/Family Support
	New Hampshire	Adult Services
	Pennsylvania	Attendant Care Services for Older Adults
	South Dakota	Attendant Care
7	Alabama	Optional Supplement of SSI
	Arkansas	Spinal Cord Commission
	California	In-Home Supportive Services Program
	Connecticut	Essential Services Program
	Connecticut	Personal Care Assistance Program
	Illinois	Community Care Program
	Illinois	Home Services Program
	Maine	Attendants for Unemployed People
	Massachusetts	Independent Living Personal Care
	Massachusetts	Personal Care Program
	North Carolina	Attendant Care
	Oregon	In-Home Services/ Project Independence
	Wisconsin	Supportive Homecare Program
	Wisconsin	Family Support Program

CHAPTER VI

PROGRAM UTILIZATION AND EXPENDITURES

The previous three chapters have described the structure of the attendant service programs in the United States as well as their development, administration, funding sources and degree of conformity to the Independent Living model. These chapters were intended to present the rules, regulations and requirements of these programs. In this chapter we propose to carry the process one step further and discuss who actually gets service from these programs and how much it costs programs to provide that service.

Service Utilization

The data in this survey indicate that approximately 850,000 people in the U.S. received publicly-funded attendant services through 135 programs.[21] The state with the greatest number of attendant service consumers in FY1984 was California, with 150,805 people (or 0.64% of the state's population) (Table 23) (U.S. Bureau of the Census, 1986). New York had the second largest number of attendant service users, 124,808 people (0.71% of New York's population). The proportion of the population receiving attendant services in any given state ranged from 0.01% to 0.87%. The total number of users represents 0.36% of the population of the United States. If the users in only three states, New York, California and Massachusetts, are excluded,

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[21] This figure is an estimate because: a) 16 programs could not report their caseload, b) there are an additional 19 programs we could not interview, c) 9 programs were eliminated from client and expenditure figures because the administrator could not break out those who received attendant services from those who got home-delivered meals, transportation and medical services. Figures from two programs received late were added into the data reported in this chapter.

this figure drops to 0.22%. Administrators of 44 programs estimated that at least 46,472 people in their states left or were kept out of institutions as a result of their programs. Twenty-two administrators estimated that 8,383 additional people could leave institutions if their programs were expanded. Both these figures would be much higher if comparable statistics from the other personal assistance program administrators were available. This issue deserves further research.

TABLE 23

COMPARISON ACROSS STATES
OF EXPENDITURES AND TOTAL CLIENTS
OF ATTENDANT SERVICE PROGRAMS[a]

State	Total Number of Attendant Service Clients (n=135)	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands) (n=140)
Alabama	24,016	.62%	$ 17,723
Alaska[b,d]	1,193	.30%	2,200
Arizona	1,500	.06%	1,696
Arkansas	5,225	.23%	10,285
California	150,805	.64%	345,445
Colorado[g]	8,867	.31%	14,719
Connecticut	10,816	.35%	23,108
Delaware	968	.16%	1,485
Florida[b,f]	22,858	.24%	21,386
Georgia[a]	6,747	.12%	7,612
Hawaii	1,709	.18%	2,875
Idaho	4,283	.45%	1,177
Illinois	16,301	.14%	33,734
Indiana	21,808	.40%	13,391
Iowa	12,605	.43%	7,849
Kansas[b]	9,057	.38%	6,137
Kentucky	7,329	.20%	6,065
Louisiana[c]			
Maine	6,013	.53%	4,804
Maryland	5,082	.12%	11,441
Massachusetts[b,d]	46,374	.81%	90,467
Michigan	43,933	.47%	69,653
Minnesota[e]	35,300	.87%	5,800
Mississippi	400	.02%	372
Missouri	31,209	.63%	14,659
Montana	6,248	.79%	1,969
Nebraska	5,429	.35%	3,286
Nevada	1,071	.13%	1,092

State	Total Number of Attendant Service Clients (n=135)	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands) (n=140)
New Hampshire	3,893	.42%	3,087
New Jersey	1,850	.03%	3,809
New Mexico	2,200	.17%	7,384
New York	124,808	.71%	504,361
North Carolina	626	.01%	1,657
North Dakota	59	.01%	192
Ohio	26,359	.24%	46,942
Oklahoma	9,130	.30%	35,395
Oregon	10,041	.38%	15,330
Pennsylvania	59,995	.51%	22,338
Rhode Island	1,578	.17%	3,754
South Carolina	9,690	.31%	14,501
South Dakota	4,020	.58%	1,910
Tennessee[b]			875
Texas	68,880	.48%	108,288
Utah	522	.04%	1,048
Vermont	362	.07%	611
Virginia	5,000	.09%	14,191
Washington	10,167	.25%	22,735
West Virginia[a]	5,177	.27%	4,814
Wisconsin	15,600	.33%	25,953
Wyoming[c]			
Dist.of Columbia	3,285	.55%	8,853
TOTAL	850,388		$1,568,458

a Data added from two additional programs from questionnaires received late from Georgia and West Virginia.

b Number does not include Title III recipients because administrator unable to isolate attendant services from adult day care, home-delivered meals, counseling and other Title III services.

c No data available.

d Alaska & Massachusetts figures do not include HHA programs. Decided they were strictly short-term.

e Minnesota does not include Personal Care Services figures.

f Florida does not include elderly waiver.

g Colorado does not include HHA program/could not separate ILP-delivered services from regular Medicaid program.

One hundred and twenty-five of the program administrators were able to report on the disabilities of the people they serve (Table 24). Almost 50% of the programs served people with all types of disabilities.

TABLE 24

NUMBER AND PERCENTAGE OF PROGRAMS SERVING PEOPLE WITH VARIOUS DISABILITIES (n=125)

Type of Disability	Programs Number	Percent
All Types	57	46%
Physical Disability, Brain Injury	35	28%
Physical Disability Only	16	13%
Physical Disability, Brain Injury, Mental Disability	10	8%
Physical Disability, Brain Injury, Intellectual Disability	5	4%
Physical Disability, Mental Disability	1	1%
Physical Disability, Intellectual Disability	1	1%

Data from 90 programs indicate that users of attendant services are largely older people (Table 25).

TABLE 25

AGE GROUPS SERVED (n=90)

Age Group	Number	Percent
Less Than 60 or 65	142,562	23%
Greater Than 60 or 65	476,851	77%

As the make-up of the aging population might lead one to expect, seventy percent of recipients are women. Eighty-one percent are white, 12% Black, 5% Hispanic, with less than 2% Native American or Asian. These figures reflect the racial composition of the population as a whole, but not necessarily of the disabled population, since a disproportionately high incidence of disability has been found among black people (Bowe, 1985).

Expenditures

Based on reports from 140 programs, total expenditures for all attendant service related programs were approximately $1,568,458,000 ($1.6 billion) in FY1984.[22] The range of expenditures per program was from a low of $2,000 (the Indiana Medicaid Waiver providing household assistance, short-term personal assistance (respite) and case management to 10 people) to a high of $458,200,000 per year (the New York Personal Care Services Program serving 52,400 people). The average per client expenditure per year was $2,862, with the median being $1,421.

The state with the highest expenditure was New York ($504m), followed by California ($345m), and Texas ($108m) (Table 23). While New York spends the most, California serves the largest

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22 Expenditures for FY1985 were used here in 33 cases for which 1984 data were unavailable. FY1983 figures were used for 4 programs. Also included are expenditures on 28 programs which include more than attendant services because attendant services could not be isolated. However, expenditures from 6 Title III programs are not included, amounting to $436 million, because they included large numbers of people receiving home delivered meals and adult day care.

number of people. This seeming anomaly is explained by the fact that New York relies heavily on more costly "personal care workers" as providers, whereas in California people needing more than 20 hours per week of personal assistance are permitted to hire less costly individual providers.

The distribution of expenditures among the various state and federal funding sources is presented in Table 26. Expenditures on attendant services are divided almost equally between federal and non-federal sources. States currently bear 40% of the expenditures on attendant services, either as the major funding source of a program or as a match with federal funds. Medicaid, the Social Service Community Block Grant Program and the states together provide 87% of the monies available for attendant services.

TABLE 26

TOTAL EXPENDITURES ON ATTENDANT SERVICES
BY FUNDING SOURCE (n=129)

Funding Source	$	%
TOTAL FEDERAL	814,404,000	52%
Title XIX		
Regular Program	384,740,000	25%
Waivers	19,294,000	1%
Title XX	320,703,000	21%
Title III	37,281,000	2%
Title VIIA	14,000	0%
Other Federal	52,372,000	3%
TOTAL NON-FEDERAL	723,375,000	48%
State	617,732,000	40%
County/Municipal	84,438,000	6%
Other	13,004,000	1%
Client Fees	7,166,000	0%
Private	1,035,000	0%
GRAND TOTAL	1,537,779,000	100%

Expenditures From Programs Not in WID Survey

The WID survey did not include programs funded by other sources such as the Veterans' Administration Aid and Attendance Allowance and Developmental Disabilities and Mental Health programs. In addition, of course, a large proportion of attendant services are either paid for by the user or provided without pay by volunteers.[23] Each of these will be discussed.

In 1984, the Veterans' Administration paid 8,493 people $101,036,520 in "Aid and Attendance Allowances" in addition to their disability pension. Of these, 6,860 received $906 per month. The remaining 1,633 people, deemed to be at risk of institutionalization, received $1,350 per month (McCarthy, 1985).

Currently, both Developmental Disability and Mental Health Services funds are being utilized to maintain individuals outside of institutions. Further investigation needs to be done to determine the extent of separately funded and administered attendant services available to these two populations.

Many individuals receive attendant services from family and friends free of charge. Still others pay for attendants on their own without public assistance of any kind. Again, the extent to which this occurs and the circumstances under which it occurs are major questions for future research.

If one combines the $1.6 billion expended by the programs surveyed by WID with the $.1 billion expended by the VA, then it appears that 1984 expenditures on attendant services amounted to

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[23] The omission of private health care insurers is not an oversight. Few health insurance policies offer even a minimal amount of home health benefits; none includes long-term attendant services (Alpha 1984).

at least $1.7 billion dollars and reached at least 859,000 people.

CHAPTER VII

AVAILABILITY OF SERVICES ACROSS THE UNITED STATES

This chapter compares the availability of attendant services across the fifty states and the District of Columbia. Nine states - Alaska, Delaware, Georgia, Louisiana, Minnesota, Montana, Tennessee, Virginia, and Wyoming - have no comprehensive attendant services program (that is, no program that combines personal maintenance and hygiene, mobility, and household assistance services) serving any of the three basic age groups-children, working age adults or older adults (Table 27). In addition, there are four states (Arkansas, Colorado, North Dakota and West Virginia) that offer comprehensive attendant services to some age groups but not all. In Colorado and Delaware, however, the lack of a combined service program is mitigated by the existence of separate household and personal maintenance and hygiene programs. In other words, in 8 states, the full range of publicly-funded attendant services are not available for people with disabilities of any age; and in 3 states services are available for some people but not others, depending on age.

In 39 states plus the District of Columbia, then, programs exist that offer attendant services to all age groups. We emphasize that the finding here is only that such programs exist; no inferences are to be drawn as to their adequacy in terms of either quality or number served. In addition, these programs differ widely in their capacity to meet the needs of disabled people in their jurisdiction because of marked variations in eligibility criteria, services offered, maximum allowances, other rules and regulations, and, most important, funding constraints.

TABLE 27

NUMBER OF PROGRAMS PER STATE OFFERING
VARIOUS TYPES OF PERSONAL ASSISTANCE BY AGES SERVED

State	Attendant			Personal Maintenance/ Hygiene and Household Separately			Personal Maintenance/ Hygiene Only			Household Only			Respite		
	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged
Alabama	3	3	2										1	1	1
Alaska[a]										1	1	2	1	1	2
Arizona	1	1	1												
Arkansas			1				1	1	1				1	1	1
California	2	2	3				1	1	1				1	1	3
Colorado		1	1	1	1	1							1	2	2
Connecticut	1	2	2		3	3	2						1	2	3
Delaware				2	2	2									
Florida	1	1	2		2	2								1	3
Georgia						1				1	1		1	1	1
Hawaii	1	1	1								1	2	1	1	1
Idaho	2	2	2									1	2	2	3
Illinois	1	1	2										1	1	1
Indiana	2	2	2			2	1	1						1	3
Iowa	2	2	2										2	2	2
Kansas	1	1	1		3	3	1							1	2
Kentucky	1	2	3										1	2	3
Louisiana															
Maine	5	5	5										1	2	2
Maryland	3	3	3										2	3	2
Massachusetts	2	4	3				1	1	1				1	2	2
Michigan	2	1	2										1		1
Minnesota[b]							1	1	1						1
Mississippi	1	1	1									1			
Missouri	2	2	3		2	3	1						1		2
Montana[b]										2	2	3	1	1	1
Nebraska	1	1	1		2	2	1						1	1	1
Nevada	1	1	1		2	3	1						1	1	1
New Hampshire	2	2	2							1	2	2	1	2	2
New Jersey	3	3	3										1	2	2

State	Attendant			Personal Maintenance/ Hygiene and Household Separately			Personal Maintenance/ Hygiene Only			Household Only			Respite		
	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged	Child	Adult	Aged
New Mexico	1	2	2							2	2	3	1	1	1
New York	3	3	3								1	1	3	2	4
North Carolina	2	2	2										1	1	1
North Dakota		1	1												
Ohio	4	4	5										3	3	4
Oklahoma	1	1	1							1	1	1	1	1	1
Oregon	1	2	2										1	1	1
Pennsylvania	2	2	2									1			1
Rhode Island	1	2	2							1	1	1	1	1	1
South Carolina	1	2	2										1	2	2
South Dakota	1	2	2					1	1						
Tennessee												1			1
Texas	3	4	4										1	2	3
Utah	2	2	2								1	1	1	3	3
Vermont	1	1	1				1	1	1				1	1	1
Virginia[b]											2	2		1	1
Washington	1	2	2											1	1
West Virginia[b]		1	1								1	1		1	1
Wisconsin	3	2	2				1	1	1				4	3	3
Wyoming												1			1
Dist.of Columbia	1	1	1							1	1	1	1	1	1

[a] Alaska had 9 people receiving "personal care" services as exceptions to the General Medical Relief Program. This is not reflected in the table, and the program no longer exists.

[b] Minnesota, Montana, Virginia and West Virginia have somewhat better services than the table suggests because the programs listed as purely household assistance actually have "personal care" components, but they do not meet our criteria for full personal maintenance/hygiene services.

The extent of availability of short-term (respite) services is encouraging but also must be interpreted with caution. Six states offer no short-term services for any age group: Arizona, Delaware, Louisiana, Mississippi, North and South Dakota (Table 27). Six states offer no short-term services for disabled children: Florida, Indiana, Kansas, Virginia, Washington and West Virginia. Four states offer no short-term services to children or working age adults: Minnesota, Pennsylvania, Tennessee or Wyoming. And two states, Missouri and Michigan, do not have short-term services available for disabled working age adults. Even though there are 34 states with short-term services available for all age groups, it must be emphasized that the quality and quantity of the short-term services available is not equivalent across these programs. Programs range from providing 24-hour/day services for a week or two to merely providing one- to two-hours of services. Some require the individual who is disabled to move into a hospital or institution while family members or regular attendants are free to go wherever they like. Other programs provide the services in the disabled person's home.

CHAPTER VIII

NEED VS. ADEQUACY OF THE SYSTEM TO MEET THAT NEED

Estimating the number of people in the United States who could use personal assistance services is a very difficult task[24]. Three comparatively recent studies have attempted to address the issue.[25] One of these - the Home Care Supplement to the 1979-1980 National Health Interview Survey (NHIS) - is used as the basis for discussion here because it was the only study that collected data nationwide. In addition, it includes all age groups, was conducted fairly recently and has the most conservative estimates.

Conducted by the U.S. Bureau of the Census, the NHIS involved interviewing a sample of civilian, non-institutionalized people in the U.S. over a period of two years. Respondents were asked whether they received or needed the assistance of another person in performing seven basic physical activities: walking, going outside, bathing, dressing, using the toilet, getting in or

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[24] See DeJong, G. and Sager, A. (1977) for a fuller discussion of the problems of need estimation from the various existing studies.

[25] Connell, Vagnoni and Vafeas (1984, p. 41) conducted a random sample telephone survey to estimate the total number of users of both personal and domestic services in Pennsylvania. Results showed that 1% of Pennsylvanians between the ages of 18 and 64 and 5.76% of those over 65 used assistance from another person on either a weekly or daily basis. DeJong and Sager (1977, p. 40) prepared an estimate of the number of people in Massachusetts needing some help from another person with personal care, on an intermittent or steady basis, based on previous national surveys as well as a 1972 study in Ohio and the 1974-75 Branch-Fowler Survey of the elderly and chronically disabled in Massachusetts. DeJong and Sager estimate that in Massachusetts, 1.1% of children, 1% of working age adults and 17.7% of older people require some help, while the number of adults of all ages requiring assistance on a regular basis is less than half of these figures.

out of bed or chair, and eating. The percentage of people needing help with one or more physical activities was: 0.23% of children under the age of 17, 0.67% of adults between the ages of 17 and 64, and 6.67% of adults over 65 years old (Czajka, 1984, p. 39). In all likelihood these figures understate the number of people needing attendant services. They do not include people who need assistance with household maintenance tasks such as housework, meal preparation and shopping.[26] They also do not include the institutional and nursing home population who could live in the community if adequate personal assistance were available.

Table 28 compares the NHIS estimates of need with the WID data on the number of people being served. This comparison indicates that 74,473 children who need personal assistance services do not get them from the public programs surveyed for this study.[27] There are an estimated 758,938 working-age adults and 903,202 people 65 or older who need assistance but do not get it from public programs surveyed here.[28] All told, then, there are an estimated 2,134,111 non-institutionalized people needing personal assistance who do not receive it from the publicly-

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[26] The survey did ask about people needing assistance with four household maintenance tasks but results have been reported in a way that cannot produce unduplicated counts of people needing help with both household and personal maintenance.

[27] This may be an overestimate of children not receiving services because specifically Developmental Disabilities programs were not included in the WID survey.

[28] The cut-off point for older adults is not precise because some programs, mainly Title III, used age 60 and others used age 65. For the most part the figures on older people represent people over age 65 because much fewer people are receiving attendant services from Title III programs.

funded, community-based attendant service programs in the WID survey. If the 8,493 veterans who receive Aid and Attendance Allowances (McCarthy, 1985) are subtracted, then a more accurate estimate would be that there are at least 2,125,618 non-institutionalized people who are not receiving publicly supported, community-based attendant services who could benefit from such services.

TABLE 28

COMPARISON OF HOME CARE SURVEY ESTIMATES
OF NEED FOR ASSISTANCE WITH PERSONAL MAINTENANCE TASKS
WITH NUMBER ACTUALLY BEING SERVED IN PUBLICLY FUNDED PROGRAMS
FROM WID SURVEY

Age Group	1984 Total U.S. Population	Home Care Survey		WID Survey	
		% Needing Help With 1 or More Tasks	# Needing Help With 1 or More Tasks	% Being Served	# Being Served (FY84)
Children (17 & under)	62,688,000 (under 17)	.23%	144,182	.10% (under 18)	59,527
Adults (18-64)	145,430,000 (17-64)	.667%	970,018	.09% (18-60 or 65)	136,062
Aging (65+)	28,040,000 (65+)	6.67%	1,870,268	2.34% (60 or 65+)	654,798

To make this estimate more complete, we must go one step further and consider the institutional population. There were 118,982 mentally retarded people in institutions in 1982, 1,303,000 nursing home residents in 1977 and 232,340 people with mental disabilities in institutions in 1979, totaling about 1.7 million people (Czajka, 1984, pp. 13-17). If one assumes that half these people could live at home with adequate personal assistance, then the number of people who may not be receiving community-based publicly supported attendant services who could benefit from such services could be estimated at 2,975,618 (3 million).

The average cost per user of attendant services from the WID study amounts to $2,840 for all types of service. If this figure is multiplied by the estimated number of people not being served, 3 million, then the additional expense could be estimated to be approximately $8.5 billion. Not all of this estimated $8.5 billion would need to be new money, however. Some of the needed funds could be obtained by diverting Medicaid funds now going into institutional and nursing home care as has been proposed by Senators John Chaffee (Rhode Island) and Bill Bradley (New Jersey) (Senate Bill 873, 1985). Money could also be diverted from the more costly contract agency mode of service delivery to the less costly independent provider mode whenever feasible, thereby freeing up dollars for new users. Money could also be saved by combining programs in a state in order to eliminate duplication of administrative costs.[29] Nor would the source of new money need to be public funds. Private insurers may eventually take some responsibility for underwriting the costs of personal assistance services (Alpha, 1984). More immediately, as more attendant programs encourage people to work and 1619 becomes a reality, some users would bear part of the costs of personal assistance services according to a sliding scale and/or begin paying taxes on earned income (see footnote 4, p. 7).

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[29] Currently, the state of Wisconsin has been considering ways to combine its personal assistance programs, for example.

CHAPTER IX

CONCLUSIONS AND RECOMMENDATIONS

As this study clearly indicates, there is no comprehensive system of attendant services in the United States. There is no broad federal policy; rather, scattered references to personal assistance services are found embedded in policies established by Congress and federal agencies with respect to programs such as Medicaid and the Older Americans Act. Consequently, jurisdiction over federal personal assistance programs is divided among several different agencies. The programs that exist are funded by a wide variety of federal and non-federal sources. Responding to what they perceive as a major need, states have developed their own policies and programs, usually (but not always) making use of those disparate federal funding sources that are available. States have generally failed to benefit from the experience of other states, apparently because until recently there has been little if any communication between them. All this has resulted in personal assistance services which are fragmented, lack coordination, usually medically oriented, burdened with work disincentives, inequitably distributed across the United States, and delivered by personal assistants who are poorly paid.

The lack of a federal personal assistance policy has affected the lives of at least 3.8 million Americans of all ages with disabilities who presently are either receiving personal assistance services which may be inadequate or who are receiving no publicly-funded services at all. Many of these people are denied independent lives because they are forced to either 1)

depend on relatives and other volunteers for personal assistance, 2) live in institutions because no community-based personal assistance services are available, or 3) make do with less than adequate services from a variety of providers over whose services they have little or no control.

It is the responsibility of organizations of disabled people and older people as well as the general public to begin making Congress aware of the impact on people's lives that the lack of a comprehensive, funded national personal assistance policy has had. The World Institute on Disability is committed to working with people throughout the country towards the establishment of a comprehensive, nationally-funded personal assistance policy. We know how critical these services are to people with disabilities everywhere and from our first hand experience in California, we have seen the benefits such services provide. The results of this survey have reinforced WID's awareness that the lack of a comprehensive national personal assistance policy consistent with the principles of independent living has contributed to the unnecessary isolation and dependency of untold numbers of Americans with disabilities.

Given this situation, our foremost recommendation is that a federal personal assistance services policy consistent with the principles of independent living be established and that a national personal assistance program be developed. This program should be funded by the federal government and private insurers and implemented by the states in accordance with policies and regulations promulgated at the federal level. Just as it took the enactment of Medicare, Medicaid and the Older Americans Act

to ensure that older people and poor people receive a more equitable share of this country's medical care and social services, it is now necessary to institute a National Personal Assistance Service Program in order to make personal assistance services available across the United States to all those who could benefit from them.

There are many different groups of people - including policy makers, advocates, and people of all ages with physical, mental, and intellectual disabilities - who support the establishment of adequate, equitable community-based personal assistance services. If these groups and individuals come together in a broad national coalition, they might make rapid progress toward the development of a national personal assistance service.

To this end **WID Recommends: 1) that meetings of federal and state policy makers with representatives of and advocates for people of all ages with all types of disabilities be convened and funded by the federal government. The purpose of these meetings would be to discuss the implications of this study and WID's recommendation in order to develop proposals regarding the development of a national personal assistance program for independent living; and 2) that the federal government study what other countries have done to incorporate personal assistance services into their national social service policy.**

We now present a series of other policy and action recommendations which should guide the development of a National Personal Assistance Services Program. The first twelve of these were adopted by the National Attendant Care Symposium sponsored by the National Council on the Handicapped. The remaining four

policy recommendations have been developed by WID as a result of its research. Following each policy recommendation is a discussion of the reasoning behind it and a series of recommendations for action in accordance with each suggested policy.

RECOMMENDATIONS

1. The program should serve people with all types of disabilities on the basis of functional need. The WID survey results indicate that people with physical disabilities are eligible to be served by all the programs, but programs vary as to whether they will also serve people with other disabilities such as brain injury (90%), mental or psychiatric disability (62%) and intellectual disability or mental retardation (60%).

Personal Assistance services have traditionally been conceived as meeting the needs of persons with physical disabilities. The term, however, rightfully includes any assistance which compensates for an individual's functional limitations. In this sense, many consider interpreters for persons with hearing disabilities, readers for persons with visual disabilities, and social guidance for persons with mental and intellectual disabilities to fit within this category. A good example of a program already taking this approach is Title III of the Older Americans Act which has geared its services to older people on the basis of functional difficulty rather than diagnosis. As a consequence, the list of services covered by Title III includes attendant services as well as communication and cognitive assistance.

Few would question the need to provide personal assistance

services to people whose disabilities are so substantial that they need assistance for several hours a day or more. It must be borne in mind, however, that these services can also be essential to people who need much smaller amounts of time. Recipients of In-Home Supportive Services in California, for example, receive an average of 12 hours of service a week. Even if the need for personal assistance may be minor in terms of the time required, having it met may nevertheless be a crucial link in an individual's support system for independent living.

WID Recommendations: 1) that every state make personal assistance services available to people with disabilities of all kinds; 2) that more information be gathered on the availability, type of services offered and quality of separate personal assistance service programs for people with intellectual, mental and sensory disabilities; 3) that the extent of need for personal assistance services to these three populations be explored; and 4) that demonstration projects be funded that combine services to these three groups with services to people with physical disabilities and brain injury.

2. The Programs Should Serve People of All Ages. There are two issues involved here: 1) the need for people of all ages to be able to get personal assistance services, and 2) the need to combine in one program services for people of all ages. The survey results show that people over 60 or 65 are served by almost every program in the country; adults between the ages of 18 and 60 or 65 can receive services from three-fourths of the programs. However, such options are much less likely to be available to children (and their parents). Indeed, in six

states, parents of children with disabilities can receive no services at all for their children (Table 22). In addition, only 41% of the programs serve people of all ages. The rest serve single age groups or various combinations: 26% serve all those over 18 years old; 24% serve older people only; 4% serve only children and 6% only those between 18 and 65.

The need for services for disabled adults of all ages generally is not contested. However, the necessity to provide personal assistance services to children with disabilities is still not widely accepted.

Outside assistants could assume responsibility for at least part of the extra time (that is, time over and above what is normally required by a non-disabled child of the same age) that needs to be devoted to meeting the needs of a child with a disability. Making such assistance available could reduce financial and emotional stress in the family and enhance development of independent living in children and adolescents.

Combining personal assistance programs for people of all ages (and disabilities) can only help to reduce administrative costs, avoid duplication and foster fruitful exchange of ideas for service delivery. The fact that so many existing programs successfully serve all age groups demonstrates that this is well within the realm of feasibility. The State of Wisconsin has already instituted discussions between the heads of the various personal assistance programs in Wisconsin to explore ways to combine them and avoid duplication of expenditures and services. Other states should follow suit.

WID Recommendations: 1) that every state make personal

assistance services available to all age groups; 2) that projects be established to look at how children and adolescents who are disabled can benefit from attendant services; and 3) that states begin the process of consolidating programs for different age groups.

3. The program should provide for the optimum degree of self-direction and self-reliance as individually appropriate and offer the users a range of employer/employee and contract agency relationships. Currently approximately a quarter of the programs offer service users a choice between individual providers who are more or less managed by the service user and contract agency workers or government staff who tend to be much less consumer oriented. In addition, some of the 34 programs which use individual providers are in states which also have separate programs using contract agencies. Users in these states may thus also have a choice, although this choice may be more theoretical than real, since most programs which rely on individual providers have smaller caseloads.

At its maximum, self-direction involves locating, interviewing, screening, hiring, managing, paying, evaluating and terminating personal assistants. Various of these functions, such as locating, interviewing and screening, may be performed by an agency or other third party while the individual maintains control of other tasks, such as hiring, management, payment and termination. For persons with limited cognitive function, more third party involvement and supervision may be required; such individuals, however, should still be able to maintain control to a degree consonant with their ability. The issue of user control

is of extreme importance to The Independent Living Movement because often people with disabilities never develop (or, having once developed it, lose) the ability to be independent because other people take charge of their lives.

WID Recommendations: 1) that all programs allow users the choice of individual providers or trained home health aides and homemakers from public or private agencies; and 2) that a continuum for managing service delivery be made available, ranging from consumer management (to the maximum extent feasible) to total agency management; and 3) that users of short term periodic services also have the option to locate, screen, train, hire and pay attendants if desired; and 4) that policies be developed that presume consumers prefer self-direction and require an evidential finding that an individual does not want or is incapable of total self-direction.

4. The program should offer assistance with personal, cognitive, communicative, household and other related services. The survey results show that personal assistance service programs vary widely with respect to the types of service provided. Currently only a third of the programs offer what we would consider a comprehensive service package of attendant and household assistance services, including catheter management. Very few programs offer readers (19%) or interpreters (13%), even though these services are often essential to people with impaired vision or hearing if they are going to function effectively. We suspect that even fewer programs offer cognitive services such as money management. Generally these services, if they are available at all, are provided by separate programs.

Personal assistance programs need to provide attendant services, communication assistance, and cognitive assistance or assistance with any other tasks which are essential to the maintenance of independence and productivity for persons with any type of disability. In some states these services are currently fragmented into separate programs so that the number of people going into a person's home is often needlessly increased. Efficiency and continuity are enhanced by allowing any assistant to perform any task, instead of limiting one provider's duties to personal hygiene and management services and another's to household assistance, for example.

WID Recommendations: 1) that all rural and urban areas in the U.S. have a program offering the full array of personal assistance services needed by disabled people of all ages and all disabilities - physical, intellectual, mental and sensory; 2) that the states which offer services through separate household assistance and personal hygiene and maintenance services programs establish new programs which combine these services in terms of service delivery as well as organizational structure.

5. The Program should provide services 24 hours a day, 7 days a week, as well as short-term (respite) and emergency assistance as needed. Two-thirds of the programs in the survey offered services 24 hours a day, seven days a week, and more than half the programs offer some sort of short-term services. This is a good beginning, but obviously it is not adequate. Although we did not ask specifically about emergency services, few program administrators mentioned them when given the opportunity to identify additional services not listed in the questionnaire. It

is our impression that emergency back-ups for independent providers, if they exist at all, can be found through the Independent Living Programs.

Personal assistance services are life-sustaining in many cases and therefore their availability should obviously not be limited to certain hours. Programs should have back-up assistants available on a short-term or emergency basis to fill in the inevitable gaps that occur in the personal support systems of individuals with extensive disabilities. In cases where the bulk of services are provided by family members or friends, these arrangements are much less likely to break down if services are available on a short-term as well as emergency basis.

WID Recommendations: 1) that all programs make services available 24 hours a day, 7 days a week; 2) that a pool of emergency assistants be maintained in every locality; 3) that short-term services be established for all age groups in the 16 states that do not offer them and 4) that short-term services be available for longer periods (2 - 4 weeks) or less on a regular or periodic basis; and 5) that short-term and emergency services be provided in the location the user requests, instead of being restricted to institutional settings.

6. The program should serve people at all income and resource levels on a cost sharing basis as appropriate and employment disincentives should be eliminated. The vast majority of existing programs discourage people from working. Only 36% of them had graduated cost-sharing formulas. Only 10 programs had an income ceiling above $15,000 a year.

Without any public assistance at all, a single person with

an extensive disability requiring approximately 20 hours of personal assistance service per week would need, at barest minimum, $15,000 a year in income, i.e. $5,200 to pay his or her attendant plus a very modest $9,800 for living expenses, not to mention any disability-related expenses that might arise.

A major disincentive to employment would also be eliminated if Medicaid benefits or other provisions for health care could be made available to disabled workers if they are unable to obtain other health insurance. Currently, unless one is fortunate enough either 1) to work in a large organization with a non-restrictive group policy, 2) to live in the State of Wisconsin, which has a state insurance fund for the disabled (Griss, 1985), or 3) to be eligible for Medicaid under Section 1619 of the Social Security Act (see footnote 4, p. 7), it is almost impossible for people with disabilities to obtain health insurance.

WID Recommendations: 1) that all personal assistance service programs establish an appropriate cost-sharing formula and a realistic income ceiling from which all reasonable disability-related expenditures are excluded; and 2) that Medicaid benefits or other federal health insurance be made available to disabled workers who are unable to obtain private health insurance at reasonable cost.

7. Services should be available wherever they are needed (eg. at home, work, school, on recreational outings, or during travel). Currently personal assistance services are rarely available outside the home unless a disabled individual employs his or her own assistant. Few programs provide attendants in work, school,

or recreational settings or for out-of-town trips. Services are provided only to the extent necessary to keep someone functioning at home or, in the case of children, functioning at school.

WID Recommendations: 1) that personal assistance be made available to users, not only for personal maintenance, hygiene and mobility tasks and housework, but also for work, school and recreation needs as well; 2) that eligibility requirements not limit the geographic mobility of the individual, so that people needing personal assistance are allowed to travel outside a state and still retain coverage for personal assistance services; and 3) that employers in both the private and public sectors explore the possibility of making personal assistants available in the workplace as is already being done in Sweden (Ratzka, 1986).

8. Personal Assistants should receive reasonable remuneration and basic benefits. The poor quality of attendants and the high rate of attendant turnover are major concerns for program administrators and consumers alike. This is directly attributable to the low wages that all types of attendants receive ($3.87/hour for individual providers and about $4.75/hour for contract agency and government workers) and the minimal benefits (usually none) that contract agency workers and independent providers receive (Table 14).

WID Recommendations: 1) that attendants be paid at least 150% of the minimum wage with periodic increases to reflect inflation and growth in experience and qualifications; 2) that attendants receive paid sick leave, vacation and group health insurance benefits in addition to Social Security, worker's compensation and unemployment benefits; 3) that joint

discussions between unions and users be instituted to explore ways in which users and assistants can work together to provide better benefits for each other.

9. Training for administrators and staff of administering agencies and provider organizations should be provided.

Because personal assistance for independent living is relatively new as a human service profession, and because a definite philosophical foundation underlies the delivery of these services, it is unlikely that new program administrators and staff will have the knowledge or experience necessary to take the proper approach in operating such programs. It is therefore essential that they be trained and inspired by people who are thoroughly knowledgeable about personal assistance services, both in conceptual and practical terms.

WID Recommendations: 1) that the legislation establishing the program (as well as the implementing regulations) require that administrators and agency personnel undergo appropriate training; and 2) that qualified disabled persons who use personal assistance services play a significant role in this training nationwide.

10. The program should provide recruitment and training of personal assistants as appropriate. The issue of training for personal assistants is receiving much attention across the country. Besides contract agency training programs, some community colleges and technical schools are offering courses as well as some ILPs. The controversy regarding these programs centers on the degree to which independent living philosophy is taught, the degree to which assistants are encouraged to look to

their clients for training in their particular needs, and the level and type of training (and perhaps licensure) necessary for assistants who will be working with people with intellectual or mental disabilities.

Some people prefer to hire totally untrained assistants and personally train them to meet their specific needs. Others would rather only consider assistants who have already been screened as to their personal qualifications and experience. Those with intellectual or mental disabilities and brain injury who require assistance in financial management, adherence to medication schedules and other tasks are likely to need assistants who can pass very strict tests of character, reliability and experience.

WID Recommendations: 1) that all personal assistant training programs be imbued with the Independent Living philosophy; 2) that training programs be managed and administered by the Independent Living Centers, wherever possible; 3) that personal assistants be taught that, whenever possible, the bulk of their training will be provided by their clients; 4) that users of personal assistance be instructors in the training program; 5) that training of personal assistants not be mandatory in most cases; 6) that registration and special training be required for those working with people with mental or intellectual disabilities; and 7) that personal assistant referral, recruitment and screening services be available for users who desire them.

11. The program should provide effective outreach and training of consumers as appropriate. Many people who could benefit from personal assistance services are likely to be unaware of their

availability. Effective efforts to reach out to potential users are thus essential. Effective outreach tends to increase program costs, however, so it is not surprising that programs are unenthusiastic about doing it. Programs therefore need to be required to conduct effective outreach.

Informing people that services are available is not sufficient, however. People need to be made aware of what personal assistance services are and how these services can help them live more independently and productively. People living in nursing homes or growing up with their families in dependent, sheltered environments, often have no conception of the degree of personal independence they can achieve or of the programs available to assist them in reaching these goals. Even though the independent living movement has had a considerable impact during its first 15 years of existence, there are still thousands of people who have not been touched by its precepts.

Once they become aware of the benefits of using personal assistants, many people with disabilities will need training in how to use personal assistant services to best advantage and how to establish and maintain effective working relationships with their assistants. Managing attendants is somewhat akin to operating a small business in that it requires personnel management, budgeting, employee supervision and training, payroll management and the like. A number of Independent Living Programs, being consumer-oriented, have recognized the importance of consumer training, developed training programs, and, in several cases, published training manuals (see Bibliography).

WID Recommendations: 1) that all personal assistance

service programs be required to undertake outreach efforts such as visits to rehabilitation centers, sheltered workshops and schools, as well as brochures, public service announcements on T.V. and radio, buses, and so on; and 2) that personal assistance service programs offer both training for consumers in management of personal assistants and follow-up.

12. Consumers should participate to a substantial degree in policy development and program administration. It is reasonable to assume that, except in the few cases where Independent Living Programs have taken a leading role in establishing and/or administering personal assistance programs, there has been no significant involvement of consumers in program administration and policy development. Because the issues involved are so complex and so unfamiliar to most public administrators, and because consumer control is so central to the philosophy underlying this service, it is imperative that persons who use personal assistance services be involved, not merely in an advisory or consulting capacity, but as full participants in the process of developing policy and administering personal assistance service programs.

WID Recommendations: 1) that every personal assistance service program actively recruit personal assistance users to fill administrative and management positions; and 2) that representatives of Independent Living Programs be included on policy boards and state/local commissions which establish personal assistance service policy, rules and regulations.

13. The program should not restrict individual providers from administering medications or injections or from carrying out

catheter management. Many programs define these services as medical or paramedical and only allow relatively well-paid Registered Nurses or Licensed Practical Nurses to provide them. Only 59% of the programs surveyed allowed administration of medications; 37% allowed administration of injections. Catheter management was provided by fewer than half the programs. Furthermore, in a number of states (most notably New York) where there are now no restrictions regarding paramedical services, nursing associations are campaigning to prohibit non-licensed providers from performing these tasks.

Many disabled people reasonably argue that there is no justification for such restrictions, particularly in the case of individuals able to manage their own personal assistants. These restrictions only serve to drive up the cost of personal assistance services and complicate lives of people with disabilities by increasing the number of providers with whom they need to deal.

Nowhere are concerns raised about the fact that nurses, as a matter of course, teach family members, friends and people with disabilities themselves to do tasks such as respiratory and catheter management, injections, or giving medication. Clearly, non-licensed providers as well can be trained to perform such tasks with due care. (For a fuller discussion of this issue see Zukas, 1986).

WID Recommendations: 1) that programs allow personal assistance users to train independent providers in catheter management, injections and medication administration; and 2) that programs ensure that all providers are allowed to provide the

full range of services, paramedical as well as non-medical.

14. Family members should be eligible to be employed as individual providers. Many disabled people of all ages rely exclusively on spouses or other family members for personal assistance. Currently, however, only about a quarter of the programs surveyed (41) allow family members to be compensated for their services.

In the case of adults who are disabled, when a user prefers to use a family member as an attendant, the family member should be paid for that service. The provision of personal assistance services is work; it should not be treated as forced volunteerism. Provision of money to hire an attendant should mean that anyone, related by blood or not, can be hired by the user. The issues involved here are dignity, control and choice for both the user and the provider as well as reduction of family stress.

WID Recommendation: 1) that all family members be eligible to be paid providers at a user's request; and 2) that a cash "personal assistance allowance" be provided which the disabled person can use to hire family members or to purchase services from the outside.

15. No one should enter a nursing home or institution unless a finding has been made that they cannot live at home even with personal assistance. Currently, many people enter nursing homes because alternative ways of meeting their needs either are not available or have not been considered. Once someone has entered a nursing home, it is often extremely difficult to reverse the process because family and community ties are often severed,

homes and household items have been sold, and so on.

WID Recommendation: that all states institute mandatory programs to screen prospective nursing home admissions.

16. Mechanisms for accountability should be developed that take into account the user's need for independence. The debate over whether a program should mandate that users have the choice of hiring independent providers often comes down to questions of liability. Unfortunately there may be a major conflict between users' needs for independence and the states' need to protect themselves from liability for any abuse of users by personal assistants. The fear is greatest in the case of users who are not capable of completely managing their own personal assistant and in the case of users who need more "invasive" personal assistance with injections, medications, and catheters.

WID Recommendation: that a conference of independent living activists, users and program administrators be convened to discuss the issue of liability more fully.

Over the years the United States government has developed programs, such as SSI, in order to ensure that people who are disabled or elderly would have a minimum level of income. However, income maintenance is not in and of itself sufficient to insure independent living for people who are disabled. Personal assistance, particularly attendant services, is crucial to maintaining adults of all ages who are disabled in the community.

Recognizing this fact, two key conferences were convened in 1985 by the World Rehabilitation Fund and the National Council on the Handicapped in conjunction with the World Institute on

Disability to discuss the state of personal assistance services in the U.S. and Europe. The participants at these conferences-including representatives of the Independent Living Movement, state and national disability organizations, state and federal government, researchers, consumers and advocates - all concluded, along with WID, that a national personal assistance program for independent living must be established.

Maintaining the current non-policy will no longer work. What has emerged on a de facto basis as an outgrowth of existing federal programs is a medical model of personal assistance service delivery which is unnecessarily costly and inadequate. There is an ever growing population of older people needing attending services and an increasing number of families unable to provide those services.

The situation, in short, is reaching crisis proportions. In order to deal with it, it behooves policy makers to give serious consideration to this study and the recommendations it contains.

BIBLIOGRAPHY

References

Adams, K. (1986, July). [Discussion between the World Institute on Disability staff and international organizer, Service Employees International Union]. Unpublished.

Alpha Center. (1984, May). Long-term care alternatives: Innovations in financing chronic care for the elderly. Alpha Centerpiece. Bethesda, MD: Author.

Association for Retarded Citizens. (1985). House subcommittee holds hearing on medicaid waiver program. Association for Retarded Citizens Government Report, 15(No. 13), pp 6-7.

Bowe, F. (1985). Black adults with disabilities: A statistical report drawn from census bureau data. Washington, DC: President's Committee on Employment of the Handicapped.

Connell, J., Vagnoni, J., & Vafeas, J. (1986). An assessment of attendant care needs among disabled Pennsylvanians. Philadelphia, PA: Pennsylvania Developmental Disabilities Council.

The Consolidated Omnibus Budget Reconciliation Act of 1 9 8 5 , Public Law 99-272, Section 9502. (1986).

Czajka, J.L. (1984). Digest of data on persons with disabilities. Washington, DC: Congressional Research Service, The Library of Congress. (Report no. 84-1153 EPW).

DeJong, G., & Sager, A. (1977). The need for personal care services by severely physically disabled citizens of Massachusetts. Boston, MA: Rehabilitation Research and Training Center No. 7, New England Medical Center.

DeJong, G. & Wenker, T. (1979). Attendant care as a prototype independent living service. Archives of Physical Medicine and Rehabilitation, 60, 477-482.

Griss, B. (1985). Report on health care coverage for working-aged persons with physical disabilities: A key to reducing disincentives to work. Madison, WI: Office for Persons with Physical Disabilities.

Gunterman, Emma. (1986). Correspondence regarding attendant services. Unpublished.

McCarthy, Jennifer (Assistant to Senator Alan Cranston). (1985). Personal written communication regarding Veteran Administration Attendant Services' Allowance.

Nosek, M. (1986). Personal assistance: attendant services, readers and interpreters. In appendix to Toward independence: An assessment of federal laws and programs affecting persons with disabilities with legislative recommendations. (052-003-01023-2). Washington, DC: U.S. Government Printing Office.

Oktay, J. S. & Palley, H. A. (1983). The chronically limited elderly. Home Health Care Services Quarterly, 4(2).

Oriol, W. (1985). The complex cube of long term Care: The case for next step solutions -- Now. Washington, DC: American Health and Planning Association.

Ratzka, A. D. (1986). Independent living and attendant care in Sweden: A consumer perspective. (Monograph No. 34). New York, NY: World Rehabilitation Fund.

Reaser, J. M. (1985). How are things on the home front: A report of a survey of elderly recipients of homemaker-home health aide services in four communities. Washington, DC: Research and Data Resources Department, American Association of Retired Persons.

Title 38, United States Code, Section 314(o),(p),(i),(r),(2), 1984. Rates of Wartime Disability Compensation.

U.S. Bureau of the Census. (1986). Statistical abstracts. Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services. Annual revision of the poverty income guidelines. (March 8, 1985). Federal Register, 50(46), 9517-9518.

U.S. General Accounting Office. The elderly should benefit from expanded home health care but increasing these services will not insure cost reductions. (1982). Washington, DC: Author

U.S. Senate. (1985). S.873. A bill to amend Title XIX of the Social Security Act to assist severely disabled individuals to attain or maintain their maximum potential for independence and capacity to participate in community and family life. Introduced in 99th Congress, 1st Session.

Van Nostrand, J.F. (1984). Long term care populations: Demography and projections. In The complex cube of long-term care: A national working conference, conference papers. (Tab 4, Attachment B). Washington, DC: American Health and Planning Association and The Veterans Administration.

Zola, I. K. (1986, May). Toward a unifying agenda: Some major issues cross-cutting policies and programs concerning aging and disability. Background paper for the Pew Health Policy Fellows Conference, Philadelphia, PA.

Zukas, H. (1986). Attendant services, paramedical services, and liability issues. Berkeley, CA: World Institute on Disability.

Works Consulted

General

American Health and Planning Association and The Veterans Administration. (1984). The complex cube of long term care: A national working conference, conference papers. Washington, DC: Author.

Attendant care problems prompt new laws and still there are problems. (1985, May). The Disability Rag, p.11.

Australian Council for Rehabilitation of Disabled. (1980). A National Attendant Care Allowance, a discussion paper. Australia: Author.

Bureau of Economic Research. (1985). Economic consequences of spinal cord injury. (Final Report, Project No. NAO-384). New Jersey: Rutgers, The State University of New Jersey

Cocking, P. (1981). Working paper No. 1: Population projections from the survey of handicapped persons. ACROD Disability Issues. Australia: ACROD (Australiam Council for Rehabilitation of Disabled) Limited.

Cocking, P. (1984). Working Paper No. 2: Population estimates from organisations for people with physical disabilities. ACROD Disability Issues. Australia: ACROD (Australian Council for Rehabilitation of Disabled) Limited.

CPAC: Anatomy of a grassroots effort. (1984, April). The Disability Rag, 1-5.

Deimling, G. T. & Poulshock, S. W. (1985). The transition from family in-home care to institutional care. Research on Aging, 7,(4), 563-576.

DeJong, G. (1978). Disability, home care and relative responsibility: A legal perspective. (Grant No. 16-P-57856/1-04). Boston, MA: Medical Rehabilitation Institute, Tufts-New England Medical Center.

DeJong, G. (1986, April). Speech given at the National Conference on Attendant Care, Philadelphia, PA: Sponsored by Pennsylvania Department of Public Welfare. Unpublished.

DeJong, G. (1985, September). Toward a unified agenda on the in-home attendant services. Paper presented at "Toward a Unified Agenda: A National Conference on Disability and Aging," Racine, WI: Wingspread Conference Center.

Drew, L. S. & Dunker, C. J. (1984). Employing the disabled to provide home and community services. Paper presented at the 45th Annual Conferencee of the American Society for Public Administration, Wichita, KS.

Feller, B. A. (1983). Americans needing help to function at home. NCHS Advancedata, No. 94, pp. 1-11. Washington, DC: U.S. Department of Health and Human Services.

The Flinn Foundation. (1980). The Pritzlaff Commission on long-term care in Arizona: Executive summary. Arizona: Author.

La Vol, J. & Callender, M. (1976). Home health cost effectiveness: What are we measuring? Medical Care, 14, 866-872.

Longwood, D. (1984). Private sector interest in long-term in-home attendant care. Berkeley, CA: The World Institute on Disability. Unpublished.

Mc Neil, J. (1985). Selected materials on the prevalence of disability. Washington, DC: U.S. Bureau of the Census.

Minkler, M. & Blum, S.R. (1982). Community-based home health and social services for California's elderly: Present constraints and future alternatives. (Monograph No. 13). Berkeley, CA: University of California, Institute of Governmental Studies.

National Council on the Handicapped. (1986). Toward independence: An assessment of federal laws and programs affecting persons with disablities with legislative recommendations. (052-003-01022-4). Washington, DC: U.S. Government Printing Office.

The National Study Group on State Medicaid Strategies. (1984). Restructuring Medicaid: An Agenda for Change. Washington, DC: Center for the Study of Social Policy.

New analysis of Health Interview Survey data. (1984, July/August). Programs for the Handicapped, pp. 7-10.

New Mexico Long Term Care Commission. Demographic background materials/Appendix to final report: Disabled and elderly populations. Undated.

Newacheck, P. W., Budetti, P. P., McManus, P. (1984). Trends in childhood disability. American Journal of Public Health, 74(3), 232-236.

Noelker, L. S. & Wallace R. W. The organization of family care for impaired elderly. (1985). Journal of Family Issues, 6(1), 23-44.

Nosek, M. A. (1985). Expanding attendant care options for disabled Texans: A source book. Houston, TX: Independent Living Research Utilization Project.

Nurses fight attendant care laws. (1985, August). The Disability Rag, 9.

Office of Human Development Services, Office of Policy Coordination and Review. Pre-expenditure reports: 1983 analysis of fiscal year, 1983 social services block grant. Washington, DC: Author.

Oktay, J.S. & Paley, H.A. (1981). Home health and in-home service programs for the chronically-limited elderly: Some equity and adequacy considerations. Home Health Care Services Quarterly, 2,(4), 5-27.

Paralyzed Veterans of America. (1976). Aide and attendance survey. Washington, DC: Author.

Paralyzed Veterans of America. (1982). Survey of commercial attendant care providers. Washington, DC: Author.

Pennsylvania statewide attendant care task force. Attendant care position paper. (1983). Pittsburgh, Pa: Allegheny County Department of Planning.

Poulshock, S. W. & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39(2), 230-239.

Price, R. & Arbuckle, P. (1983). Federal programs that finance home health care services. (Report No. 83-235 EPW). Washington, DC: Congressional Research Service, The Library of Congress.

Shanks, J. M. & Freeman, H. E. (1980). Executive Summary for the California Disability Survey. Sacramento, CA: Department of Rehabilitation.

Sheehan, S. (1983, November 21). A reporter at large, Kate Quinton: Part I. The New Yorker, pp. 56-134.

Sheehan, S. (1983, November 28). A reporter at larger, Kate Quinton, Part II. The New Yorker, pp. 58-138.

Smith, M. (1985). Residential and community services for persons with mental retardation and related disabilities: Background information and proposed legislation. Washington, DC: Congressional Research Service, The Library of Congress.

Soldo, B. J. (1985). In-home services for the dependent elderly: Determinants of current use and implications for future demand. Research on Aging, 7,(20).

South Carolina Vocational Rehabilitation Department. (1981). Independent living services survey. Columbia, SC: Author.

Soyka, P. W. Homemaker-home health aide services for handicapped children. (1976). Child Welfare, 55, 241-251.

The story of a compromise. (1984, April). The Disability Rag, 6-8.

Thornock, et al. (1978). Attendant care needs of the physically disabled: Institutional perspectives. Rehabilitation Literature, 39, 147-153.

Townsend, A. L. & Poulshock, S. W. (1986). Intergenerational perspectives on impaired elders' support networks. Journal of Gerontology, 41(1), 101-109.

U.S. General Accounting Office. (1981). Improved knowledge base would be helpful in reaching policy decisions on providing long-term, in-home services for the elderly. Gaithersburg, MD: Author.

Upshur, C. C. (1982). An evaluation of home-based respite care. Mental Retardation, 20, 58-62.

Vermont Center for Independent Living. (1984). A summary of Full human potential. Montpelier, VT: Author.

World Institute on Disability. (1985). Report on National Attendant Care Symposium. Proceedings from a national meeting sponsored by the National Council on the Handicapped, National Coalition of Independent Living, and the World Institute on Disability. Berkeley, CA: Author.

Zukas, H. (1982). A case for a national attendant care program. Berkeley, CA: World Institute on Disability.

Zukas, H. (1985). Summary of Federal Funding Sources for Attendant Care. Berkeley, CA: World Institute on Disability.

Independent Living

Crewe, N.M. & Zola, I. & Associates. (1983). Independent living for physically disabled people. San Francisco, CA: Jossey-Bass, Inc.

Gliedman, J. & Roth, W. (1980). The unexpected minority: handicapped children in America. New York, NY: Harcourt Bruce Jovanovich.

Independent living concept gaining national attention, federal support. (1980). Programs for the Handicapped, 1, 8-14.

Independent living [Special Issue]. (1976). Archives of Physical Medicine and Rehaiblitation, 60,(10).

Pflueger, S. (1979). Independent living: Emerging issues in rehabilitation. (RSA Contract No. 22-p. 5901 9/3-01). Washington, DC: Institute for Research Utilization.

Legislation, Rules and Regulations

Administrative Rules: Personal Care Assistance Program. OH: R.C. Chapter 119 (3304-4-01) (1982).

Assembly Bill No. 533. (1985). Nevada: Committee on Health and Welfare.

Demonstration projects relating to the training of AFDC recipients as home health aides. Section 966. Omnibus Reconciliation Act of 1980. Public Law 96-2655. (1980).

Homemaking/personal care services. Rhode Island Department of Social and Rehabilitative Services Manual. (1983). (Section 515). Providence, RI: Department of Social and Rehabilitative Services.

Older American's Act Amendments of 1984, U.S. Public Law 98-459.

Participant Directed Attendant Care Program. Regulations. Montpelier, VT: Agency of Human Services. (1983).

Personal Care Attendant Demonstration Program. (1985). Chapter 307 of Public Laws of 1985. New Jersey.

Personal Care Attendant Demonstration Program. (1986). Chapter 524 of Public Laws of 1986. New Jersey.

Personal Care Services. Proposed Rule. NY II-18 NYCRR 505.14 a-b (1985).

Senate bill No. 118. (1984). (84 BR 277/SCS). Submitted to Commonwealth of Kentucky, regular session of 1984.

The Veterans Administration. (1985). Benefits for Veterans and Dependents. Washington, DC: U.S. Government Printing Office.

Program Evaluations, Descriptions, Proposals and Reports

Birnbaum, H., Gaumer, G., Pratter, F., & Burke, R. (1984). Nursing Homes Without Walls: Evaluation of the New York state long term home health care program. Cambridge, MA: Abt Associates.

California Department of Social Services. (1983). The feasibility of implementing time-per-task standards in the In-Home Supportive Services Program. Sacramento, CA: Author.

Center for Accessible Living. (1983). Attendant care in Kentucky: What's available. Louisville, KY: Author.

Clark, A. & Fragher, J. (1986). Evaluation of the attendant care pilot project. Sydney, NY: University of Sydney, Department of Community Medicine.

Community Services Institute. (1985). Contract summary and supplemental program descriptions: Attendant care program. Narbeth, PA: Author.

DeJong, G. (1977). Meeting the personal care needs of severely physically disabled citizens in Massachusetts. Waltham, MA: Levinson Policy Institute, Brandeis University.

Department of Health and Rehabilitative Services, Aging and Adult Services. (1981). Instructional guide to assessment of individuals for aging and adult services: Client assessment forms. (HRS-AA 3003, A,B,C,D,E,F). Washington, DC: Author.

Eckoff, R. & Aalberts, N. (1985). Report to the Governor and General Assembly regarding state funding for homemaker-home health aide/chore services. Des Moines, IA: Iowa Health Department.

Florida Office of Evaluation. (1982). An evaluation of Florida's home care for the elderly and adult foster home programs. Tallahassee, FL: Author.

Greenberg, J. N., Schmitz, M. P. & Lakin, K. C. (1983). An analysis of responses to the Medicaid home and community-based long-term care waiver program. Washington, DC: State Medicaid Information Center, National Governor's Association.

Guyer, Mary E., Newell, Cindy. (1984). State of Nevada attendant care survey. Carson City, NV: Nevada Division of Rehabilitation.

Health Care Financing Administration. P. L. 97-35 Section 2176 waiver requests for home and community-based services: Description of home and community-based services initial requests, approval and effective dates as of 2/29/84. (1984). Washington, DC: Author.

Idaho Bureau of Medical Assistance. Personal care attendant program. (Undated). Internal document. Boise, ID: Department of Health and Welfare.

Idaho Office on Aging. (1984). Review of Idaho's Homemaker Services for the Elderly: State Fiscal Year 1984. Boise, ID: Author.

Illinois Department of Rehabilitation Services. Home services for the severely handicapped: Annual report, 2. Springfield, IL: Author.

Kentucky Cabinet of Human Resources. (1986). Independent care assistance network project report: July 1, 1985-December 31, 1985. Frankfort, KY: Cabinet for Human Resources.

Kentucky Cabinet for Human Resources. (1985). Staff report: Bluegrass area development district waiver project. Louisville, KY: Commonwealth of Kentucky, Division of Medical Assistance.

Krieger, M. J. & Potemken, D. (1982). Characteristics of Medicaid home and community-based waiver program applications, Vol. I: Background and Summary. (Working paper: #3198-2). Washington, DC: The Urban Institute.

Krieger, M. J. & Potemken, D. (1982). Characteristics of Medicaid home and community-based waiver program applications, Vol. II: Abstracts of state waiver applications. (Working paper: #3198-2). Washington, DC: The Urban Institute.

Laninga, D. (1986). Pennsylvania attendant care model. Memo. Harrisburg, PA: Pennsylvania Department of Public Welfare.

Laninga, D. Pennsylvania Department of Public Welfare Attendant Care Program: 1984-85 Fiscal Year. (1985). Harrisburg, PA: Department of Public Welfare, Office of Policy, Planning and Evaluation.

Markowitz, R. K. (1984). Evaluation of the Maryland Attendant Care Pilot Project. Baltimore, MD: John F. Kennedy Institute.

Maryland Department of Health and Mental Hygiene. (1985). Medical assistance personal care services utilization survey report. Baltimore, MD: Author.

Maryland Department of Health and Mental Hygiene. (1984). Report to the House Appropriatations Committee and Senate Budget and Taxation Committee on In-Home/Personal Care Services. Baltimore, MD: Author.

Maryland Department of Budget and Fiscal Planning. (1984). Review and comparison of four in-home service programs: Department of Health and Mental Hygiene: Medical Assistance Personal Care, Department of Human Resources: In-Home Aide Services, Inter-Agency Council on Aging Services (Office on Aging): Gateway II, Maryland State Department of Education: Attendant Care. Baltimore, MD: Author.

Michigan Office of Adult and Family Community Services/ Independent Living Services Unit. (1983). Home Help -- Handicapper Services Project: "Data analysis" (supplement to final report). Lansing, MI: Author.

Michigan Office of Adult and Family Community Services/ Independent Living Services Unit. (1983). Home Help -- Handicapper Services Project: Phase I: Final Report. Lansing, MI: Author.

Minnesota Department of Public Welfare. (1982). An analysis of the Department of Public Welfare's Personal Care Attendant Program. St. Paul, MN: Author.

New York Department Social Services. (1979). Contracting for personal care services and contracting for Nursing Assessment and Nursing Supervision of personal care services by social services districts. (Transmittal No.: 79 ADM-34). Albany, NY: Author.

New York Department of Social Services. (1980). Personal care services -- scope and procedures. (Transmittal No.: 80 ADM-9). Albany, NY: Author.

New York Department of Social Services. (1982). Personal care service in New York state: A profile of the population: Report 1. Albany, NY: Author.

New York Department of Social Services. (1984). Personal care services reimbursement limitations. (Transmittal No.: 84 ADM-6). Albany, NY: Author.

New Hampshire State Council on Aging. (1985). Project directory. Concord, NJ: Author.

Ohio Legislative Service Commission. (1982). Financial assistance for personal care services for severely physically disabled persons. Columbus, OH: Author.

Oklahoma Commission for Human Services. (1983). Waiver application -- aged and adult physically disabled. Oklahoma City, OK: Author.

Oregon Department of Human Resources. (1984). Title XIX waiver request. Salem, OR: Author.

Palmer, B. H. (1984). Community care for the elderly: FY 83-84, quarter 4, year end program report. Tallahassee, FL: Department of Health and Rehabilitative Services.

Pennsylvania Community Services Institute. (1985). Technical assistance plan: Attendant care program. Narbeth, PA: Author.

Pennsylvania Department on Aging. (1984). Special grants for attendant care for the elderly. (Aging Program Directive: #84-10). Harrisburg, PA: Author.

Personal care assistance -- an evaluation of the HCSB. (1985). The Disabled Washingtonian, 1,(2). Washington, DC: DC Center for Independent Living.

A Proposal for the development of personal care attendant services in Michigan.

Rhode Island Department of Elderly Affairs. (1985). Rhode Island Department of Elderly Affairs: In-home services program: Fourth annual report: July 1, 1983-June 30, 1984. Providence, RI: Author.

Rules governing medical assistance. (1983). Title III, Chapter 9. Boise, ID: Department of Health and Welfare.

Schultz, C. Testimony on the Personal Care Attendant Program. Presented before the Minnesota Senate Committee on Human Services on August 26, 1982.

Services for Independent Living. Documentation over a course of two years of pursuing a piece of legislation to bring about a state funded personal care attendant program in Ohio. (1982-1984). Euclid, OH: Author.

Smith, D. (1977). Alternatives to inpatient care in Linn County. Iowa Health Systems Agency.

Smith, G., Yoshimoto, C. K., Goto, L. S. & Tari, C. (1985). Second annual report on the Nursing Home Without Walls demonstration project. Honululu, HI: Department of Social Services and Housing.

Smith, M.F. (1985). Residential and community services for persons with mental retardation and related disabilities: Background information and proposed legislation. Washington, DC: Congressional Research Service, Library of Congress.

Tennessee Department of Human Services. (1985). Annual social services state plan for the state of Tennessee. Nashville, TN: Author.

Tennessee Department of Human Services. (1984). Survey of homemaker services. Nashville, TN: Author.

Texas Department on Aging. (1984). Biennial report: September 1982-August 1984. Austin, TX: Author.

Texas Department of Human Resources. (1985). Summary: 1915(c) model waiver program: Special targeted home and community-based services. Austin, TX: Author.

Verhage, M. (1979). Manual for evaluation of PCA services. Boston, MA: Department of Public Welfare.

Waiver under Section 2176, long-term care alternatives. Rhode Island Department of Social and Rehabilitative Services manual. (1983). (Section 305). Providence, RI: Department of Social and Rehabilitative Services.

Zukas, H., Cone, K., & Leon, J. (1984). Descriptive analysis of the In-Home Supportive Services Program in California. Berkeley, CA: World Institute on Disability.

Training Materials for Users and Attendants

Access to Independence. Working together: Disabled people and their attendants talk about attendant care. [Sound and slide show]. Madison, WI: Author.

Attendant care basics. [Videotape]. Berkeley, CA: Videotape Applied Video Services.

Berkeley Center for Independent Living. (1984). Proposal for training project. Berkeley, CA: Author.

Boston Information Center for Individuals with Disabilities. (1984). Attitudes to look for and maintain in your personal care attendant. Boston, MA: Author.

Boston Information Center for Individuals with Disabilities. (1984). How to find a personal care attendant in the greater Boston area. Boston, MA: Author.

Center for Independent Living. Attendant orientation. Berkeley, CA: Author.

League of Human Dignity. (1985). Attendant services training package. Lincoln, NE: Author.

Minnesota Department of Public Welfare. (1984). Guide to Personal Care Attendant Program for personal care attendants. St. Paul, MN: Author.

New York Department of Social Services. (1978). Training for personal care service providers. (Transmittal No.: 78 ADM-19). Albany, NY: Author.

Ohio Rehabilitation Services Commission. Attendant Care Program: Payroll tax guide. (1983). Salt Lake City, UT: Author.

Resource Center for the Handicapped. (1983). Hands helping hands: Personal care attendant training manual. Seattle, WA: Author.

Total Living Concepts, Inc. (1983). Employer's handbook for attendant services. Cincinnati, OH: Author.

Total Living Concepts, Inc. (1983). Your tax responsibilities in employing personal care attendants. Cincinnati, OH: Author.

Ulicny, G.R., Elwell, J.S, & Jones, M.L. (1984). Disabled employers can increase their attendant management skills. Independent Living Forum, 2, 1-7.

Ulicny, G. & Jones, M. (1986). Step-by-step guide to training and managing personal care attendants. Kansas City, KS: University of Kansas, Research and Training Center on Independent Living.

APPENDICES

APPENDIX A

DEFINITION OF TERMS

ACTIVITIES OF DAILY LIVING

Any of the activities which must be performed in the course of daily living. These activities include dressing, bathing, grooming, getting around, eating, preparing meals, shopping, cleaning house and engaging in work, school, community service or recreation.

ADULT DAY CARE

Provision during the day, on a regular basis, at a site outside of the home, of health, medical, psychological, social, nutritional,educational and other services that a person with a disability needs in order to remain in the community.

AREA AGENCY ON AGING (AAA)

The local planning and service units designated by the Department of Aging to administer a program of comprehensive community services for the elderly. AAAs can be a part of county government or a private non-profit agency.

ATTENDANT SERVICES

Assistance from others which compensates for a person's diminished ability to perform activities of daily living on her/his own. As used in this report and by the National Council on the Handicapped, attendant services include assistance with personal maintenance and hygiene, mobility and household maintenance tasks.

CASE MANAGEMENT

Coordination of a number of services, provided by various agencies, which are needed by a single individual. It includes assessment of client need; development of an individualized service plan; arrangement of services; and reassessment. The goal of case management is both to avoid service duplication and to facilitate an individual's receiving all needed services.

CHORE SERVICES

Infrequent tasks related to home maintenance such as repairs and yard work. Under Title XX, personal care activities and other domestic services such as shopping and housecleaning are included in this definition as well.

COGNITIVE ASSISTANCE

Assistance with life management activities such as money management, planning and decision making.

COMMUNICATION ASSISTANCE

Interpreting for people with hearing or speech disabilities.

COMMUNITY BASED SERVICES

Services provided in a disabled person's home or other settings (e.g. work, school, recreation) which enable the person to function in those settings.

CONGREGATE HOUSING

Multiple unit housing with shared common space and shared services for those disabled people who are not totally independent but who do not need institutional care.

COST SHARING

An arrangement allowing individuals with incomes above a certain minimum to receive services and pay a portion of the cost of those services according to a sliding scale based on income.

DISINCENTIVES TO EMPLOYMENT

Provisions of entitlement programs (such as SSI, SSDI and Medicaid) which discourage their beneficiaries from seeking and/or holding employment because to do so would result in loss of income and/or benefits. (See also footnote 4, page 7.)

DISABILITY

A person with a disability is any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

ESCORT

Accompanying and/or assisting a client while traveling to necessary activities, such as medical appointments, shopping, school, etc. Many attendant programs limit escort services to medical appointments only.

FUNCTIONALLY DISABLED

An impaired ability to perform activities of daily living.

HOME DELIVERED MEALS

Meals prepared at a central location and delivered to homes of people who are old or disabled on a daily basis or less frequently.

HOME HEALTH AGENCY - See HOME HEALTH SERVICES

HOME HEALTH AIDE

Person who, under the supervision of a home health or social service agency, assists older, ill or disabled persons with household maintenance and personal maintenance and hygiene tasks, and paramedical tasks. Home health aides are usually trained by the Home Health Agency or by outside training programs.

HOME HEALTH SERVICES

Home health services are services and items furnished to an individual in his or her home by a home health agency. The services are furnished under a plan established and periodically reviewed by a physician and include: part-time or intermittent skilled nursing care; physical, occupational or speech therapy; medical social services, medical supplies and appliances (other than drugs and biologicals); home health aide services; and homemaker services.

HOMEMAKER

Person who, under the supervision and training of a home health or social service agency, assists older, ill, or disabled persons with household maintenance tasks and child care.

HOUSEHOLD MAINTENANCE TASKS

Cleaning, shopping, meal preparation, laundering, heavy cleaning and repairs.

INTELLECTUAL DISABILITY

Mental retardation

INDEPENDENT LIVING PROGRAM (ILP)

A community-based non-profit organization, usually controlled by disabled people, which provides a variety of services directed at enabling disabled people to live independently. Among these services are peer counseling, personal assistance/attendant referral, benefits counseling, Independent Living Skills training, housing referral, and advocacy to remove social, economic and environmental barriers.

INDIVIDUAL PROVIDER

An attendant hired and supervised by a recipient.

LONG TERM "CARE"

The whole spectrum of services potentially needed by disabled and ill people of all ages. The range includes health care, social services, housing, transportation, income security and jobs.

MEDICAID

Joint federal-state program, created in 1965 by Title XIX (Medical Assistance) of the Social Security Act. It is administered by the states and pays for health care services for people with very low income. In some states it also pays for personal maintenance/hygiene services or attendants.

MEDICARE

Federal program, created in 1965 by Title XVIII (Health Insurance for the Aged) of the Social Security Act. It provides health insurance benefits primarily to persons over the age of 65 and others who are eligible for Social Security benefits.

MENTAL DISABILITY

Psychiatric illness

MOBILITY

Ability to move from one place to another.

NURSING HOME PRE-ADMISSION SCREENING

A process conducted prior to entry into a nursing home to assess a person's functional abilities and service needs in order to determine whether the individual can remain living in the community rather than enter a nursing home.

PERSONAL ASSISTANCE SERVICES

Assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. These tasks include: personal maintenance and hygiene tasks, mobility tasks, household maintenance tasks, infant and child care related tasks, cognitive tasks, security related services and communication services.

PERSONAL MAINTENANCE AND HYGIENE TASKS

Dressing, grooming, feeding, bathing, respiration equipment maintenance, and toilet functions such as bowel, bladder, catheter and menstrual tasks.

PROTECTIVE SERVICE

Activities to assist individuals who, because of mental or physical disability or family situation are unable to protect themselves from neglect, hazardous situations or abuse without assistance from others.

RESPITE SERVICES - See SHORT-TERM SERVICES

SECTION 1619 OF THE SOCIAL SECURITY ACT

See footnote 4, page 7.

SECURITY RELATED SERVICES

Daily monitoring by phone, special alarm systems, etc.

SHORT-TERM SERVICES

Intermittent attendant services replacing family members or other assistants on a scheduled basis which enable the individual with a disability to receive the assistance needed and be independent of the family for brief periods while allowing the family members to leave the home for anywhere from a few hours to several weeks. Short-term services are part of the continuum of personal assistance services ranging from daily service to assistance for very short periods.

SUPPLEMENTAL SECURITY INCOME (SSI)

A federal income maintenance program which provides a flat monthly grant to people who are poor, disabled or old whose resources and other income fall within certain strict limits.

SOCIAL SECURITY DISABILITY INCOME (SSDI)

A federal income maintenance program for people who become disabled after they have worked a minimum period of time depending on age at onset of disability. Payment amounts are determined by the duration and level of a recipient's prior earnings. There are no limits on a recipient's resources or other non-work related income.

STATE AGENCY ON AGING

The state-level agency that oversees the work of the Area Agencies on Aging in each state.

TEACHING AND DEMONSTRATION

Instructional services which enable recipients of attendant services to perform some or all of those services themselves.

TELEPHONE REASSURANCE

Daily or regularly scheduled telephone calls made by family, friends or volunteers to check on those who are homebound.

APPENDIX B

METHODOLOGY

Programs Surveyed and Persons Interviewed

The programs surveyed included the entire population of programs offering personal maintenance and/or household/domestic service on a long-term basis and short-term (respite) programs for disabled people of all ages in the 50 states plus the District of Columbia. Protective service programs (those aimed at preventing abuse or neglect of adults and children) were included only if the program served people on a long-term basis.

Several types of programs were not included. Due to cost considerations, programs only for people with mental illness (mental disability) or mental retardation (intellectual disability) were not included. In general, because of fragmentation of the service system, in many states these programs are separately administered and include a different service mix.

Temporary services for acutely ill or abused/neglected people, or for those in transition from hospital, nursing home, or institution to the community were not included. Vocational Rehabilitation programs which provide personal assistance monies solely for those currently receiving vocational rehabilitation services were not included. Shared attendant programs in congregate living arrangements were not included. Finally, purely household/domestic service programs were not included if there was not a "personal care" program in the state with which the domestic program could be paired.

Identification of the programs was a time-consuming process. An Independent Living Program (ILP) in each state was asked to provide WID with a list of programs and program administrators in that state. Administrators of the Title XX, Title XIX, and Title III programs were contacted in every state to determine if these programs offered long-term "personal care", domestic/household services or respite. In addition, each person contacted was asked to identify other programs in the state.

Selecting which programs to include was difficult. In general the administrator's judgment was relied on as to whether or not a program fit the criteria. However, there were three cases in which we completed the entire interview and then decided that, in fact, the program was not a long-term or short-term (respite) program for people with chronic disabilities.

In general interview the administrator of the specific program or the head of the administering public agency was interviewed. In a few cases, the state agency delegated full responsibility for administration and data collection for the program to a Center for Independent Living (e.g. ALPHA I in Maine). In these cases the administrator of the attendant program at the Independent Living Center was interviewed.

One hundred seventy-three (173) programs in the U.S. were identified as offering comprehensive or selected personal assistance services on a long-term or short-term (respite) basis. There were 154 programs included in the survey results. Three administrators refused to be interviewed. Three questionnaires arrived too late for inclusion in the data set. Thirteen Title III programs were not included because the State Agency on Aging

had no overall statewide data on the programs in their state.

Data Gathering Procedure

Data were gathered primarily through two methods, telephone survey and mail survey. Only one survey was completed by culling through reports sent to us by the program administrator. Thirty-six mail surveys were returned, of which were incomplete and had to be finished over the phone. One hundred eighteen (118) surveys were conducted entirely by phone.

Telephone Survey Procedure

The telephone survey was conducted from February to September, 1985. The procedure for the telephone surveys involved several steps. Potential respondents were identified as described above. These administrators were then called to verify that their program delivered some or all of the constellation of attendant services as we defined them. When an administrator agreed to be interviewed, an appointment was set at least two weeks hence. A copy of the questionnaire was then mailed immediately to the respondent so she or he could gather the necessary regulations and statistics for the interview itself. The interviews were conducted primarily by two members of the WID staff with some assistance from the principal investigator. All the completed questionnaires were reviewed by the principal investigator for internal consistency. If discrepancies were found, the respondent was called again to clarify the problem.

Mail Survey Procedure

The mail survey was conducted from September 1985 to mid-January 1986. As in the phone survey, potential respondents were

first called to verify if the program met our definition of attendant services. If it did, the questionnaire was mailed for the respondent to fill out and return; if it was not returned in two weeks as requested, a reminder was mailed. If the survey still did not arrive, the respondent was called and a phone interview was arranged. All returned questionnaires were reviewed for internal consistency and respondents were called to clear up discrepancies.

Instrumentation

The questionnaire was developed by reviewing current reports on attendant services from Pennsylvania (Connell et al., 1986) and Texas (Nosek, 1986), and an extensive review of the literature. The questionnaire went through several revisions as a result of WID staff input. A more open-ended questionnaire was pretested in Illinois. A revised, more close-ended question format was tested again in Missouri, Colorado, Massachusetts and Connecticut, from which the final version was constructed.

Reliability

Responses to questions were intended to be based primarily on objective, written data in the form of agency rules, regulations, budgets and annual reports. Consequently it was assumed that the answers were unaffected by who the respondent was, the date of the interview or the date the questionnaire was completed.

However, states vary markedly in the sophistication or even the existence of management information systems, annual reports and even regulations. In some cases, respondents appeared not to

have a particularly good grasp of their programs, because either management information systems were poor or the administrator was new to the program or not close enough to the day-to-day administration of the program to know precisely the services offered, eligibility requirements, and the like. In the latter situation, when an administrator knew little about a particular program aspect, we attempted to interview other people involved in program administration to flesh out the data.

The expenditure and case load data are not as precise as one would want for several reasons. First, programs varied in their use of fiscal or calendar year. We asked for FY 83/84 or calendar year 1984 data whenever possible. Two programs could only provide 1983 data, twenty-eight programs had information for FY 84/85 only and three programs gave us their budget estimates and case load goals for FY 85/86. No attempt was made to convert these figures to 1984 levels using the consumer price index or other means.

Second, the expenditure and case load data is not precise because data collected from seven programs serving older people were not included. Administrators of these programs could not break out expenditures and numbers using attendant services from the total program. In these seven programs the bulk of the program appeared to be aimed at home-delivered meals and adult day "care" programs. Their inclusion would have greatly distorted the expenditure and case load data.

Finally, it must be noted that we were trying to capture a moment in time in a constantly shifting picture. Since we stopped conducting interviews, several new programs have been

implemented and several no longer exist. By the time this document is published, more may start. In addition, several states are actively in the process of modifying existing programs. At least one state is looking into consolidation of all its programs. Other states are considering or have already changed eligibility criteria. And, as discussed in the body of the report, Section 1619 of the Social Security Act should have a major effect on who is eligible for attendant services.

Validity

The key aspect of validity that must be considered here is whether the concepts and definitions established here were sufficiently clear and precise to insure that anyone else doing the survey would arrive at the same results. In particular, much rests on whether the programs surveyed in fact are short-term (respite), personal management/hygiene, household maintenance or attendant programs including both types of services, which serve people who are disabled on a long term basis.

It is possible that some programs surveyed do not in fact meet these criteria. Distinguishing Medicaid "personal care" programs which are aimed mainly at people who are chronically ill and in need of significant amounts of medical services on an intermittent basis from attendant programs was especially difficult. Often we had to rely on the administrator's judgments as to whether their programs fit our criteria. The opposite problem occurred with program administrators who had a very narrow conception of attendant services, e.g. programs for severely disabled working age people who are employed or employable. In these cases, we had to push administrators to

agree that if, for example, their program served older people for only an hour or two a week on a regular basis, that it was in fact an attendant service program.

Finally, we may also have missed some programs that should have been surveyed because none of our informants in a state knew about the program.

There is another issue surrounding the validity of the results which must also be mentioned. At times, respondents told us that there was a difference between what a program was actually like and what it was supposed to do on paper. In particular, we found that on paper some programs providing services through independent providers did not offer assistance with catheters, medication and injections, but that providers actually did perform such services. In order to avoid the discrepancy, we asked respondents to tell us what was in the program rules and regulations, but this may not always have occurred.

Operational Definitions

All variables used in this report, except "need for attendant services", are derived from answers to the questionnaire (Appendix C).

Administering Agency

Administering agency was created by establishing seven categories: 1) General Social Service Agencies included Departments of Social Services, Human Resources, Community Services or Public Welfare, and Mixed Departments like Health and Rehabilitation Services; 2) State Agencies on Aging; 3) State vocational rehabilitation agencies; 4) Medical Assistance

Agencies; 5) State Health Departments; 6) Centers for Independent Living; and 7) Other miscellaneous administering agencies for developmental disability, visual disability and spinal cord injury.

Age Groups Served and Eligible

For age groups eligible, several categories were derived: 1) All ages, 2) 18 and above, 3) 60 or 65 and above, 4) 18-60 or 64, 5) Less than 18, 6) Less than 60 or 65. Because Title III uses 60 as the cut-off point and most other programs use 65, the cut-off in programs serving older adults was not sharp.

For age groups served, in addition to the variations regarding the age cut-off for older adults, many programs could not specify the percentage of clients under 18 years old or over 75. So age groups served was only broken into two categories: 1) Less than 60 or 65, and 2) More than 60 or 65.

Average Hourly Reimbursement Rate

Average hourly reimbursement rate to contract agencies was determined in two ways. If an administrator could answer the question directly, then that answer was used (n=50, 42%). If an administrator could only speak in terms of reimbursement for each type of worker (n=37), e.g. home health aide, chore worker and/or housekeeper, then an average rate was derived from the highest and lowest of these reimbursement rates. Every attempt was made to include only those professions which provide attendant services in these figures, so the reimbursement rates for health personnel such as registered nurses and the various types of therapists were excluded from the range.

Average Hourly Wage

Average hourly pay for attendants was determined differently for each type of provider. For individual providers and government employees, if the administrator could answer the question directly, that answer was used. If the answer was given in terms of a salary range, then the lower end of the range was used. If the salary was in terms of days, e.g. $20/day, then that salary figure was divided by the number of hours to be worked.

The administrators of 26 contract programs were able to state what the average wage rates were in their programs. In another 37 cases, however, administrators could only give the wages for specific types of workers, such as home health aides and housekeepers. Again, excluding health personnel such as R.N.s and therapists, the average of the lowest and highest of these rates was used, as above.

Average Number of Benefits

Average number of benefits provided was obtained by giving one point for each of seven benefits the program actually provides and averaging the sum across all the programs within a particular provider type.

Disability Groups Served and Eligible

Although the questionnaire asked respondents to indicate whether they served people with developmental disabilities using three different definitions, it became clear that there were wide discrepancies in the use of the term. In order to decrease the confusion, only four categories for disability were used: 1) physical disability, 2) brain injury, 3) mental illness, and 4)

mental retardation.

Expenditure Per Client

Expenditure per client per year was computed by dividing expenditures by the number of clients. For all programs, the expenditure and client figures used were parallel. Expenditures and clients for attendant services only (n=91) were preferred. If one or the other or both were not available, then expenditures and clients in the total program were used (n=30). However, if the total program included home-delivered meals or adult day care. Then expenditure per client was not computed.

Funding Sources

If a program received funding from a federal program and combined that with state or local funds, that program was counted only as a federally-funded program under the appropriate federal Title or mix of Titles.

Graduated Shared Cost Formula

Whether programs employed a graduated shared cost formula was determined directly from the answer to that question in the survey.

Hours Services Available

Hours Services Available was defined by whether programs offered services 24 hours a day, 7 days a week as determined by answers to two questions in the survey instrument.

Income Eligibility and Poverty Level

Income eligibility was determined by asking for the highest amount an individual could earn and still be eligible for the

program, taking into account graduated shared cost formulas and deductions from income for disability-related and other expenses. It was difficult for many administrators to answer this questions with precision.

Poverty level was determined by one of two criteria: 1) the income eligibility level stated was at or below the poverty level as outlined by the U.S. Department of Health and Human Services (1985), and 2) no income eligibility level was stated but the program only accepted people who received or were eligible for SSI, SSDI or Medicaid.

Independent Living Score

A program's independent living score was computed by giving a score of 1 for a positive answer to the following 10 items: 1) no medical supervision, 2) offers attendant services with catheterization, 3) service limit of 20 hours/week or more, 4) services available 24 hours a day, 7 days a week, 5) income limit greater than or equal to 150% of the poverty level for a single person, 6) independent providers allowed, 7) user hires and fires the attendant, 8) user pays the attendant, 9) user trains the attendant, and 10) user participates in deciding the number of hours and type of services she or he requires. The higher the score, the greater the conformity to the Independent Living model of service delivery.

Maximum Service Amount Allowed

Programs stated the maximum amount of services allowed in two ways: 1) Number of hours per week, month or year, or 2) Monthly financial allowance or ceiling. If limits were defined

by numbers of hours per month or year, these were converted to number of hours per week on the assumption that the hours were equally spread - but there were programs that allowed for fluctuations within a year or over a month and did not cut off service. The monthly allowances or ceilings were converted into number of hours allowed per week by dividing by the average hourly wage for all types of attendants ($4.41/hour) and further dividing by 4 to get a weekly figure. Programs that gave the maximum amount of service allowed in terms of visits were not included because visits could be much less or much more than an hour long. Once all the service limits were converted to hours, programs could then be divided into those which allowed for 20 hours or more of service per week and those which did not - a measure of the severity of the disabilities of the program users.

Medical Supervision Required

Whether medical supervision was required was determined by adding together those programs that required supervision of all services and those requiring medical supervision of only some services.

Need for Attendant Services

Need for attendant services was defined by results from the Home Care Supplement to the 1979-1980 National Health Interview Survey in which respondents were asked whether they received or needed the assistance of another person in performing seven basic physical activities. The physical activities included: walking, going outside, bathing, dressing, using the toilet, getting in or out of bed or chair, and eating. The percentage of people in

each age group needing help with one or more activities was then used to estimate the number needing help, utilizing 1985 population census data.

Purpose of Program

Purpose was split into three categories by combining answers to the question on purpose: 1) Prevention of institutionalization and enabling people to stay in their own homes were combined, 2) Allowing people to work and still receive financial aid for attendant services and financial aid to employed or employable were combined, and 3) cost containment.

Relatives Allowed as Attendants

Whether relatives were allowed to be paid attendants was determined by whether one of the four closed-ended questions or the open-ended question regarding circumstances under which relatives can be paid were answered. If none of these questions was answered in the affirmative, then it was deduced that relatives were not paid to be attendants by the program.

Services Offered

Services offered was determined by answers to 33 close-ended questions in the survey instrument. Administrators were asked to state what existed in the regulations, not what custom allowed. In addition, a core of services was defined in order to determine if a minimum set of services was being delivered by any particular program. The personal maintenance/hygiene services core included feeding, bathing, dressing, bowel and bladder care, oral hygiene, and grooming and transfers. The household

maintenance core included light cleaning, laundry, shopping, meal preparation and clean-up. Attendant services were defined as programs that combined both personal maintenance/ hygiene and household maintenance services. In addition, personal maintenance and attendant services were described as being offered with or without catheter assistance.

Total Expenditures

Total attendant program expenditures were based on answers to one of two questions. If the administrator could state the total expenditure just on attendant services, that was the figure used (n=110). If the attendant service expenditures could not be broken out from total program expenditures, then total program expenditures were used (n=30). However, if adult day care and/or home-delivered meals were part of the total program, then the expenditure figure was not used at all because it would greatly inflate program costs. Also, if medically oriented services were included in the total program expenditure figure, that figure was not used.

Total Number of Clients

Total number of clients was defined by the answer to two questions. If an administrator could state the total number of clients receiving just attendant services, that was the figure used (n=104). If attendant services users could not be broken out from the rest of the program clients, the number of clients in the total program was used (which was the case for 20% of the programs, n=28). However, if the total program included adult day care and/or home-delivered meals, the client figure was not

used at all because it would have greatly inflated the number of attendant users, particularly in Title III programs. The client figures for programs that could not separate attendant service users from the regular Medicaid program was also not used.

Type of Provider

Type of provider was defined by answers to the questions regarding type of provider in the survey instrument which had three categories: 1) self-employed individuals, 2) contract agencies, and 3) local government unit staff.

Year Program Implemented

The year program was implemented was based directly on answers to that question.

Suggestions for Further Research

Following are questions for further research, answers to which would help to fill out the picture of attendant service delivery in the United States:

1) How many people are in need of publicly-funded attendant services?

   a) How many people could leave nursing homes and institutions if adequate attendant services were available in their home community?

   b) To what extent do people of all ages needing personal assistance rely on unpaid/volunteer labor of family and friends?

2) Are consumers in more independent living-oriented programs more satisfied with personal assistance services they receive than people in more medically-

oriented programs?

3) How do unit costs (e.g. cost per service hour) compare across the different personal assistance programs?

4) What is the impact of personal assistance services on the development of children and teenagers?

5) To what degree do personal assistance users participate in personal assistance program policy determination, administration and staff training?

6) What are all the other disability-related costs personal assistance users have to bear in order to function independently in the community, e.g. equipment replacement and repair, housing and clothing adaptations, medical insurance (if available), transportation?

7) How do personal assistant services vary for people with mental, intellectual or physical disabilities? Can services be adequately combined?

8) How do personal assistance programs compare in terms of quality?

9) How can outreach to potential personal assistance users be made more effective?

10) What other personal assistance services could people who are disabled use, e.g. emergency backups, child maintenance assistance?

11) What could contribute to increasing provider satisfaction and decreasing turnover?

12) How would providing personal assistants on the job

contribute to increasing the employment of disabled people?

13) Are people who rely on the assistance of volunteers (family and friends) less independent? less productive?

14) What is the economic and emotional impact on families who provide the bulk of attendant services for the family member who is disabled?

APPENDIX C

SOURCES OF ATTENDANT SERVICES IN THE UNITED STATES

Alabama

Community Alternative Services
Alabama Medicaid
2500 Fairlane Dr.
Montgomery, AL, 36130

Community Services Program (Title III)
Commission on Aging
502 Washington Ave.
Montgomery, AL, 36130

Homebound Program
Division of Rehabilitation
& Crippled Children's Services
2129 E. South Blvd.
P.O. Box 11586
Montgomery, AL, 36111-0586

Optional Supplement of SSI
Department of Pensions and Securities
64 N. Union St.
Montgomery, AL, 36104

Alaska

Homemaker Program
Department of Health and Social Services
Pouch H-05
Juneau, AK, 99811

Title III Services
Older Alaskans Commission
Pouch-C, Mail Stop 0209
Juneau, AK, 99811

Arizona

Pima County Community Services System
Aging and Medical Services Department
2250 N. Craycroft
Tucson, AZ, 85712

Arkansas

In-Home Services Program
Department of Human Services
Donaghey Building
7th and Main
Little Rock,AR, 72201

Spinal Cord Commission Program
Spinal Cord Commission
2020 W. 3rd, Ste. #2-H
Little Rock, AR, 72205

Title III In-Home Services Program
Central Arkansas Area Agency on Aging
706 W. 4th, P.O. Box 5988
North Little Rock, AR, 72119

California

Community Services Program--Title III
Department of Aging
1020 19th St.
Sacramento, CA, 95814

In-Home Medical Care Waiver
Department of Health Services
714 P St. Rm. #1640
Sacramento, CA, 95814

In-Home Supportive Services
Department of Social Services
744 P. St., M-S 9536
Sacramento, CA, 95814

Multipurpose Senior Services Program (Frail Elderly Waiver)
Department of Aging
1600 9th St. Rm. #456
Sacramento,CA, 95814

Colorado

Home- and Community-Based Service Program
Department of Social Services
1575 Sherman Ave.
Denver, CO, 80203

Home Care Allowance
Department of Social Services
1575 Sherman St. Rm. #803
Denver, CO, 80203

Medicaid Home Health Agency Services
Bureau of Medical Services
Department of Social Services
1575 Sherman, Room 803
Denver, CO, 80203

Supportive Services
Division of Aging and Adult Services
1575 Sherman St. Rm. #803
Denver, CO, 80203

Connecticut

Essential Services Programs
Department of Human Resources
110 Bartholomew Ave.
Hartford, CT, 06106

Fairfield County Home- and Community-Based Waiver
Department of Income Maintenance
110 Bartholomew Ave.
Hartford, CT, 06106

Medicaid Home Health Care Services
Department of Income Maintenance
110 Bartholomew Ave.
Hartford, CT, 06106

Personal Care Assistance Program
Department of Human Resources
110 Bartholomew Ave.
Hartford, CT, 06106

Promotion of Independent Living
Department on Aging
175 Main St.
Hartford, CT, 06106

Delaware

Homemaker Program
Division of Economic Services
Delaware State Hospital
P.O. Box 906
New Castle, DE, 19720

Medical Assistance Program
Delaware State Hospital, Biggs Bldg.
New Castle, DE, 19720

Florida

Community Care for Disabled Adults
Department of Health and Rehabilitative Services
1317 Winewood Blvd.
Bldg 2, Ste. #328
Tallahassee, FL, 32301

Community Care for the Elderly
Health and Rehabilitative Services
1321 Winewood Blvd.
Tallahassee, FL, 32301

Elderly Waiver/Physically Disabled and Infirm Elderly
Health and Rehabilitative Services
1317 Winewood Blvd.
Tallahassee, FL, 32301

Home Care for the Elderly
Department of Health and Rehabilitative Services
1317 Winewood Blvd., Building 2
Tallahassee, FL, 32301

Title III Program
Department of Health and Rehabilitative Services
1317 Winewood Blvd.
Bldg 2, Rm. #321
Tallahassee, FL, 32301

Georgia

Community Care for the Elderly
Office of Aging
878 Peachtree St. N.E.
Atlanta, GA, 30309

Homemaker Program
Department of Human Resources
878 Peachtree St., N.E.
Atlanta, GA, 30309

Title III In-Home Services Program
Office of Aging
878 Peachtree St., N.E.
Atlanta, GA, 30309

Hawaii

Chore Services Program
Department of Social Services and Housing
P.O. Box 339
Honolulu, HI, 96809

Nursing Home Without Walls
Community Long-Term Care Services
Department of Social Services and Housing
33 S. King St., Rm. #223
Honolulu, HI, 96813

Title III Program
Area Agency on Aging
650 S. King St.
Honolulu, HI, 96813

Idaho

Homemaker Program
Idaho Office for the Elderly
State House
Boise, ID, 83720

Special Targeted Home- and Community-Based Service Waiver
Department of Health and Welfare
450 W. State, 6th Floor
Boise, ID, 83720

Statewide Home- and Community-Based Care (Personal Care Waiver)
Department of Health and Welfare
450 W. State, 6th Floor
Boise, ID, 83720

Illinois

Community Care Program
Illinois Department on Aging
421 E. Capitol Ave.
Springfield, IL, 62706

Home Services Program
Department of Rehabilitation Services
622 E. Washington
Springfield, IL, 62705

Indiana

Home Care Services and Aging Programs
Department on Aging and Community Services
251 N. Illinois St., Capitol Center
Indianapolis, IN, 46204

Medicaid Home Health Program
Department of Public Welfare
100 N. Senate
Indianapolis, IN, 46204

Medicaid--Waivered Services
Department of Public Welfare
100 N. Senate
Indianapolis, IN, 46204

Title III--In-Home Services
Department on Aging and Community Services
251 N. Illinois St., Capitol Center
Indianapolis, IN, 46204

Iowa

Homemaker Health Aid
Iowa Department of Health
Lucas State Office Building
Des Moines, IA, 50319

In-Home Health Program
Department of Human Services
Hoover Building, 5th Floor
Des Moines, IA, 50319

Kansas

Alternate Care Program
Department of Social and Rehabilitation Services
1st Floor Biddle Bldg.
2700 W. 6th
Topeka, KS, 66606

Home- and Community-Based Services Waiver Program
Department of Social and Rehabilitation Services
1st Floor Biddle Bldg.
2700 W. 6th
Topeka, KS, 66606

Homemaker Program
Department of Social and Rehabilitation Services
1st Floor Biddle Bldg.
2700 W. 6th
Topeka, KS, 66606

Title III Program
Department on Aging
610 W. 10th
Topeka, KS, 66612

Kentucky

Bluegrass Home- and Community-Based Service Waiver
Division of Medical Assistance
Cabinet of Human Resources
275 E. Main St.
Frankfort, KY, 40601

Home Care Program (60+)
Division of Aging Services
Cabinet of Human Resources Building
Frankfort, KY, 40621

Personal Care Attendant Program
Department of Social Services
Cabinet of Human Resources Building
Frankfort, KY, 40621

Louisiana

In-Home Services Program (Title III)
Governor's Office of Elderly Affairs
P.O. Box 80374
Baton Rouge, LA, 70898

Maine

Attendants for Employed People
Alpha I
169 Ocean St.
S. Portland, ME,
Attendants for Unemployed People
Alpha I
169 Ocean St.
S. Portland, ME,

Home- and Community-Based Waiver Program
Department of Human Services
State House Station II
Augusta, ME, 04333

Homebased Care Program
Department of Human Services
State House Station II
Augusta, ME, 04333

Support Services
Bureau of Social Services
221 State St.
Augusta, ME, 04333

Maryland

Attendant Care Program
Division of Vocational Rehabilitation
200 W. Baltimore St.
Baltimore, MD, 21201

Gateway II
Office on Aging
301 W. Preston, Rm. #1004
Baltimore, MD, 21202

In-Home Aide Services
Department of Human Resources
300 W. Preston Rm. #403
Baltimore, MD, 21201

Personal Care Program
Department of Health and Mental Hygiene
300 W. Preston Rm. #206
Baltimore, MD, 21201

Title III In-Home Services Program
Office on Aging
301 W. Preston, Rm. #1004
Baltimore, MD, 21201

Massachusetts

Home Care Program
Executive Office of Elder Affairs
38 Chauncy St.
Boston, MA, 02111

Home Care Waiver Program
Department of Public Welfare
Medicaid Division Rm. #740
600 Washington St.
Boston, MA, 02111

Independent Living Personal Care Program
Medicaid--Department of Public Welfare
600 Washington St. Rm. #740
Boston, MA, 02111

In-Home Services for the Blind
Commission for the Blind
110 Tremont St.
Boston, MA, 02108

Personal Care Program
Massachusetts Rehabilitation Commission
Statler Office Building
Boston, MA, 02116

Title III
Executive Office of Elder Affairs
38 Chauncy St.
Boston, MA, 02111

Michigan

Alternative Care Program
Office of Services to the Aging
P.O. Box 30026
Lansing, MI, 48909

Home Help Program
Department of Social Services
Commerce Bldg Ste. #710
300 S. Capitol
Lansing, MI, 48912

Model Home- and Community-Based Services
Medicaid Policy and Reimbursement Division
P.O. Box 30037
Lansing, MI, 48909

Minnesota

Personal Care Services Program
Department of Human Services
Space Center
444 Lafayette Rd.
St. Paul, MN, 55101

Title III--In-Home Services Program
Board on Aging
204 Metro Square
7th and Robert
St. Paul, MN, 55101

Mississippi

Homemaker Program
Council on Aging
301 West Pearl St.
Jackson, MS, 39201

Independent Living--Attendant Care Pilot Program
State Department of Rehabilitation Services
P.O. Box 1698
Jackson, MS, 39215-1698

Missouri

Disabled Children's Home- and Community-Based Waiver
Department of Social Services
308 E. High St.
Jefferson City, MO, 65101

Home- and Community-Based Waiver for the Aged
Department of Social Services
308 E. High St.
Jefferson City, MO, 65101

Personal Care Assistance Program
Division of Vocational Rehabilitation
2401 E. McCarty
Jefferson City, MO, 65101

Personal Care Services
Department of Social Services
308 E. High St.
Jefferson City, MO, 65101

Title III--Chore Homemaker
Department of Social Services
P.O. Box 1337
Jefferson City, MO, 65102

Title XX--SSBG In-Home Service Program
Division on Aging
Broadway State Office Building,
P.O. Box 88
Jefferson City, MO, 65103

Montana

Home Attendant Program
Department of Social and Rehabilitation Services
Box 4210
Helena, MT, 59601

Home Attendant/Chore Program
Department of Social and Rehabilitation Services
Box 4210
Helena, MT, 59601

Home- and Community-Based Services Program
Department of Social and Rehabilitation Services
111 Sanders
Helena, MT, 59601

Personal Care Attendant Program
Department of Social and Rehabilitation Services
111 Sanders
Helena, MT, 59601

Nebraska

Chore Services Program
Department of Social Services
Box 95026
Lincoln, NE, 68509

Disabled Persons & Family Support Program
Department of Social Services
Box 95026
Lincoln, NE, 68509

Long-Term Care Program
Department of Social Services
Box 95026
Lincoln, NE, 68509

Title III In-Home Services Program
Department on Aging
Box 95044
Lincoln, NE, 68509

Nevada

Aging Services
Department of Human Resources
505 E. King St. Rm. #101
Carson City, NV, 89710

Attendant Care Program
Northern Nevada CIL
190 E. Liberty
Reno, NV, 89501

Homemaker Services
Welfare Division
251 Jeannell Dr.
Carson City, NV, 89710

Medicaid Home Health Program
Department of Human Resources
251 Jeannell Dr.
Carson City, NV, 89710

New Hampshire

Adult Services
Department of Human Services
Division of Welfare
Hazen Dr.
Concord, NH, 03301

Home- and Community-Based Care
for the Elderly and Chronically Ill
Office of Medical Services
Hazen Dr.
Concord, NH, 03301

Personal Care Attendant Program
Office of Medical Services
Hazen Dr.
Concord, NH, 03301

Title III-B In-Home Services
State Council on Aging
105 Loudon Rd.
Concord, NH, 03301

New Jersey

Community Care Program for Elderly and Disabled
Division of Medical Assistance and Health Services
CN 715
Trenton, NJ, 08625

In-Home Services Program (Title III)
Division on Aging
363 W. State St.
Trenton, NJ, 08625

Model Waiver (Home- and Community-Based Services for Blind or Disabled Children and Adults)
Division of Medical Assistance and Health Services
CN 715
Trenton, NJ, 08625

Personal Attendant Program
Department of Human Services
222 South Warren Street, 2nd Floor
CN700
Trenton, NJ, 08625

Personal Care Assistant Program
Division of Medical Assistance and Health Services
CN 715
Trenton, NJ, 08625

New Mexico

Coordinated Community In-Home Care for the Aged and Disabled
Human Service Department
P.O. Box 2348
PERA Bldg. Rm. #418
Santa Fe, NM, 87504

Critical In-Home Care Program
Department of Social Services
P.O. Box 2348
PERA Bldg. Rm. #516
Santa Fe, NM, 87504

Homemaker Program--Title XX
Social Services Division
P.O. Box 2348
Santa Fe, NM, 87504-2348

Title III--In-Home Services
State Agency on Aging
2214 East Palace Ave.
Santa Fe, NM, 87501

Waiver for Medically Fragile Children
Human Service Department
P.O. Box 2348
PERA Bldg. Rm. #418
Santa Fe, NM, 87504

New York

Disabled Children's Program
Office of MR & DD
44 Holland Ave.
Albany, NY, 12229

Long-Term Care Project
Division of Medical Assistance
40 N. Pearl St.
Albany, NY, 12243

Personal Care Services
Department of Social Services
1 Commerce Plaza
Albany, NY, 12237

Respite Demonstration Project
Department of Social Services
40 N. Pearl St.
Albany, NY, 12243

Title III-B and Community Services for the Elderly
Office for the Aging
Empire State Plaza
Bldg 2, 4th Floor
Albany, NY, 12243

Title XX Program
Department of Social Services
40 N. Pearl St., 9th Floor
Albany, NY, 12243

North Carolina

Attendant Care Program
Metrolina Independent Living Center
1012 S. Kings Drive, Suite G-2
Charlotte, NC, 28283

Community Alternatives Program
Division of Medical Assistance
1985 Umstead Dr.
Raleigh, NC, 27603

Homemaker/Chore Program (Title XX)
Division of Social Services
325 N. Salisbury St.
Raleigh, NC, 27611

In-Home Services Program (Title III)
Division on Aging
1985 Umstead Dr.
Raleigh, NC, 27603

North Dakota

Personal/Attendant Care Program
Department of Human Services
Capitol Building
Bismarck, ND, 58505

Ohio

Assistance for Independent Living
Department on Aging
51 W. Broad St., 9th Floor
Columbus, OH, 43266-0501

Homemaker-Home Health Aide Demonstration Project
(Title XIX Waiver)
Department of Human Services
30 E. Broad St.
Columbus, OH, 43215

Passport
Department of Human Services
30 E. Broad St.
Columbus, OH, 43215

Personal Care Assistance Program
Rehabilitation Services Commission
4656 Heaton Rd.
Columbus, OH, 43229

Title III--In-Home Services
Department on Aging
50 West Broad St.
Columbus, OH, 43266-0501

Title XX--In-Home Services
Department of Human Services
30 E. Broad St., 30th Floor
Columbus, OH, 43125

Oklahoma

Home Maintenance Aide Program
Department of Human Services
P. O. Box 25352
Oklahoma City, OK, 73125

Non-Technical Medical Care
Department of Human Services
312 N.E. 28th
Oklahoma City, OK, 73125

Title III In-Home Services Program
Department of Human Services
P.O. Box 25352
Oklahoma City, OK, 73125

Oregon

In-Home Services
Senior Services Division
313 Public Service Bldg
Salem, OR, 97310

Pennsylvania

Attendant Care Demonstration Program
Department of Public Welfare
Rm. #529, Health and Welfare Building
Harrisburg, PA, 17120

Attendant Care Services for Older Adults
Department of Aging
231 State St.
Harrisburg, PA, 17101

Community-Based Services
Department of Aging
231 State St.
Harrisburg, PA, 17101

Rhode Island

Homemaker Program
Department of Human Services
600 New London Ave.
Cranston, RI, 02920

Independent Living Rehabilitation Program
Vocational Rehabilitation
40 Fountain St.
Providence, RI, 02903

In-Home Services Program
Department of Elderly Affairs
79 Washington St.
Providence, RI, 02903

Medicaid Waiver Program
Division of Medical Services
600 New London
Cranston, RI, 02920

South Carolina

Community Service Program (Title III)
Commission on Aging
915 Main St.
Columbia, SC, 29201

Home- and Community-Based Waivered Services Program
Health and Human Services Finance Commission
P. O. Box 8206
Columbia, SC, 29202-8206

SSBG--Homemaker Program
State Health and Human Services Finance Commission
P.O. Box 8206
Columbia, SC, 29202

South Dakota

Attendant Care Program
Adult Services and Aging
700 N. Illinois St.
Pierre, SD,

Attendant Care Program
Prairie Freedom Center for Disabled Independence
800 West Ave., North
Sioux Falls, SD, 57104

Homemaker/Home Health Aide Program
Adult Services and Aging
700 N. Illinois St.
Pierre, SD,

Tennessee

Title III--In-Home Services
Commission on Aging
Tennessee Bldg, Ste. #710
535 Church St.
Nashville, TN, 37219

Texas

Family Care Program
Department of Human Resources
Mail Code 543-W, P.O. Box 2960
Austin, TX, 78769

1915-C Model Waiver
Department of Human Resources
P.O. Box 2960, Mail Code 540 W.
Austin, TX, 78769

Primary Home Care Program
Department of Human Resources
Mail Code 543-W, P.O. Box 2960
Austin, TX, 78769

Title III--In-Home Services
Department on Aging
P.O. Box 12786, Capitol Station
Austin, TX, 78711

Utah

Homemaker--Personal Care Program
Division of Aging and Adult Services
105 W. North Temple
Salt Lake City, UT, 84103

Personal Attendant Care Program
Department of Social Services
150 W. North Temple Ste. #234
Salt Lake City, UT, 84103

2176 Waiver---Home- and Community-Based Services Program
Department of Health
150 W. North Temple
P.O. Box 45500
Salt Lake City, UT, 84145

Vermont

Participant Directed Attendant Care
Vocational Rehabilitation Division
Osgood Guilding
Waterbury, VT, 05676

Personal Services Program
Division of Social Services
103 S. Main St.
Waterbury, VT, 05676

Virginia

Adult Services Program--Homebased Services
Department of Social Services
8007 Discovery Dr.
Richmond, VA, 23288

Homemaker/Personal Care, Home Health Aide,
or Companion Program (Title III)
Department for the Aging
101 N. 14th St., 18th Floor
Richmond, VA, 23219

In-Home Personal Care Services
Department of Medical Assistance Services
109 Governor St.
Richmond, VA, 23219

Washington

Chore Services Program
Department of Social and Health Services
Office Building 43-G
Olympia, WA, 98504

Comprehensive Options Program Entry System
Bureau of Aging and Adult Services
Office Building, 43-G
Olympia, WA, 98504

West Virginia

Chore Services Program
Deptartment of Human Services
1900 Washington St. E.
Charleston, WV, 25305

Home- and Community-Based Services
Medicaid Waiver for the Elderly and Disabled
Department of Human Services
1900 Washington St., E, Bldg. 6
Charleston, WV, 25305

Wisconsin

Community Options Program
Office of Program Initiative
1 W. Wilson Rm. #314
Madison, WI, 53707

Family Support Program
Developmental Disabilities Office
P.O. Box 7851
Madison, WI, 53707

Katie Beckett Waiver Program
Department of Health and Human Services
P.O. Box 309
1 W. Wilson St.
Madison, WI, 53701

Medicaid Home Health Program
Department of Health and Human Services
P.O. Box 309
1 W. Wilson St.
Madison, WI, 53701

Respite Care Project
Division of Community Services
Office on Aging
Room 480, One W. Wilson Street
Madison, WI, 53707

Supportive Home Care--Title XX
Office of Program Initiative
Division of Community Services
1 W. Wilson St. Rm. #314
Madison, WI, 53707

Wyoming

Community-Based In-Home Services Demonstration Contracts
Commission on Aging
Hathaway Building
Cheyenne, WY, 82002

Homemaker Program - Title XX
Division of Public Assistance and
Social Services
Hathaway Bldg., Rm. #388
Cheyenne, WY, 82002

Washington, D.C.

Home Care Services Program
Department of Human Services
19th and Massachusetts Ave., S.E.
Bldg 16, D.C General Hospital
Washington, DC, 20003

In-Home Support Services
Department of Human Services
Randall Bldg, 1st and "I" St., S.W.
Washington, DC, 20024

Title III In-Home Services Program
Office on Aging
1424 K. St. N.W., 2nd Floor
Washington, DC, 20005

APPENDIX D

SURVEY INSTRUMENT (QUESTIONNAIRE)

WORLD
INSTITUTE
ON DISABILITY

1720 Oregon Street, Suite 4 • Berkeley, California 94703 • (415) 486-8314

STATE _____

TITLE OF PROGRAM _____

CASE NUMBER _____

DATE _____

INTERVIEWER _____

RESPONDENT _____

TITLE _____

AGENCY NAME _____

ADDRESS _____

_____

TELEPHONE ( ) _____

_____

FOR INTERVIEWER COMMENTS:

_____

_____

_____

_____

_____

A. HISTORY

A1. Is this a medicaid waiver program?

Yes	 1
No	 2
D/K	 8

IF NO, SKIP TO A3

A2. When did HCFA approve the waiver?

SKIP TO A5

SKIP TO HERE

A3. What is the legislation which established this program? _____

A4. When was the legislation passed? _____

SKIP TO HERE

A5. When was the program implemented? _____

A6. What is the mission or purpose of the program?

	Yes	No	D/K
1. Prevent institutionalization	1	2	8
2. Contain costs associated with long-term care	1	2	8
3. Allow people to work and still receive financial aid for attendant services	1	2	8
4. Enable people to stay in their own home and community	1	2	8
5. Financial aid to employer or employable ...	1	2	8

6. Other _____

_____

B. SERVICES

B1. Which of the following services are provided by the program? (Circle all that apply.)

	Yes	No	D/K
PERSONAL CARE			
1. Respiration	1	2	8
2. Bowel and Bladder Care	1	2	8
3. Feeding	1	2	8

	Yes	No	D/K
4. Bathing	1	2	8
5. Dressing	1	2	8
6. Menstrual Care	1	2	8
7. Ambulation	1	2	8
8. Moving into and out of bed	1	2	8
9. Oral Hygiene and grooming	1	2	8
10. Skin Care	1	2	8
11. Care and assistance with prosthesis	1	2	8
12. Catheterization	1	2	8
13. Injections	1	2	8
14. Medication	1	2	8
15. Range of Motion	1	2	8

16. Other _____

_____

DOMESTIC SERVICES

	Yes	No	D/K
1. Light Cleaning	1	2	8
2. Heavy Cleaning	1	2	8
3. Laundry	1	2	8
4. Shopping	1	2	8
5. Meal preparation	1	2	8
6. Meal cleanup and menus	1	2	8
7. Chore Services	1	2	8
8. Repairs, Maintenance, Renovation	1	2	8

9. Other _____

_____

RELATED SERVICES

	Yes	No	D/K
1. Transportation	1	2	8
2. Protective Supervision	1	2	8
3. Escort	1	2	8
4. Teaching and demonstration	1	2	8
5. Respite Care	1	2	8
6. Telephone Reassurance	1	2	8
7. Readers	1	2	8
8. Interpreters for Deaf	1	2	8
9. Home Delivered Meals	1	2	8
10. Case Management	1	2	8

11. Other _____

_____

B2. Under this program what is the maximum limit on the:

1. Number of visits allowed per week ..... _____
2. Number of hours of care allowed per week . _____
3. Monthly financial allowance ..... _____
4. Total cannot exceed cost of being in nursing home ..... _____ (specify amount)
5. Other _____

_____

6. Program has no maximum limits (circle)

B3. During what hours is attendant service available?

	Yes	No	D/K
1. 24 hours per day	1	2	8
2. 9-5 only	1	2	8
3. Other _____ (specify)			

B4. During what days is attendant care service available?

	Yes	No	D/K
1. Every day	1	2	8
2. Weekdays only	1	2	8
3. Other _____			

C. ELIGIBILITY CRITERIA

C1. Is eligibility for this program based on criteria which are:

	Yes	No	D/K
1. Statewide	1	2	8
2. Countywide	1	2	8

3. Other _____

_____

C2. What age groups are eligible for the program? **IF RESPONDENT CANNOT BREAK DOWN FIGURES IN THIS WAY, USE THEIR CATEGORIES AND RECORD ON DOTTED LINE.)**

	Yes	No	D/K
1. Less than 18 years old	1	2	8
2. 18-64 years old	1	2	8
3. 65 years old and over	1	2	8

C3. Which of the following are criteria for eligibility in this program? (Circle all that apply.)

	Yes	No	D/K
1. Employed	1	2	8
2. Unemployed	1	2	8
3. Vocational Rehabilitation clients	1	2	8
4. SS 'pients or eligibles	1	2	8
5. SSDI recipients or eligibles	1	2	8
6. Medicaid recipients or eligibles	1	2	8
7. AFDC recipients	1	2	8

IF NOT EMPLOYED, SKIP TO QC5.

IF EMPLOYED,

C4. Is there a minimum number of hours per week a person must be employed to be program eligible and if so, what is it?

1. Minimum Hours = _____
2. No Minimum (circle)

SKIP TO HERE

C5. What is the maximum yearly income a person may have and still be eligible?

$ _____
N/A (circle)

IF N/A, SKIP TO C7

C6. What expenses, if any, can be excluded from a person's income when determining eligibility?

	Yes	No	D/K
1. Taxes	1	2	8
2. FICA	1	2	8

	Yes	No	D/K
3. Anything Mandatory for employment (e.g. uniforms, union dues, pension, lunches, transportation)	1	2	8
4. Impairment-related work expenses	1	2	8
5. Day Care Costs	1	2	8
6. Typical medical expenses	1	2	8
7. Health insurance payments	1	2	8

8. Other _____

_____

SKIP TO HERE

C7. What are the maximum assets a person may have and still be eligible?

$ _____
N/A (circle)

IF N/A, SKIP TO C9

C8. What property can be excluded from a person's assets when determining eligibility?

	Yes	No	D/K
1. Home	1	2	8
2. Personal items in the home	1	2	8
3. Car	1	2	8
4. Burial Insurance	1	2	8
5. Life Insurance	1	2	8

6. Other _____

_____

C9. Is there a graduated shared cost formula?

Yes 1
No 2
D/K 8

C10. Are any of the following criteria for eligibility in this program? (Circle all that apply)

	Yes	No	D/K
1. At risk of institutionalization	1	2	8
2. Wheelchair user	1	2	8
3. Able to manage own attendant	1	2	8
4. Currently living in nursing home	1	2	8
5. Living alone	1	2	8

	Yes	No	D/K
6. Family members unable or unwilling to do attendant care	1	2	8
7. Physician's orders	1	2	8
8. Resident in certain geographic area	1	2	8
Specify _____			
9. Severely disabled according to Social Security Definition	1	2	8
10. Member of specific disability group	1	2	8
Specify group _____			
11. Inability to use certain number of limbs ...	1	2	8
Specify # _____			

12. Other _____

_____

C11. Was every applicant who met the eligibility criteria ·rved in FY 1984?

Yes 1
No 2
D/K 8

IF YES OR D/K, SKIP TO QC13

C12. How many people were on the waiting list in FY 1984? _____

SKIP TO HERE

C13. How many people applied for services, but were considered ineligible in FY 1984? _____

D. CARE PROVIDERS

D1. Which of the following types of attendant care providers are there under this program?

	Yes	No	D/K
1. Self-Employed Individuals (includes family members)	1	2	8
2. Contract Agencies	1	2	8
3. Local Government Unit Staff	1	2	8

4. Other _____
(specify)

IF SELF-EMPLOYED, CONTINUE
IF CONTRACT AGENCY, SKIP TO D10
IF LOCAL GOVERNMENT UNIT SKIP TO D 17

D2. Are there specific regulations or guidelines relative to receiving attendant care from a self-employed individual?

Yes 1
No 2
D/K 8

IF NO OR D/K SKIP TO D5

IF YES,

D3. What are they?

	Yes	No	D/K
1. Attendant must receive some type of training	1	2	8
2. Attendant must be 18 years old or older ...	1	2	8
3. Consumer has to be able to supervise attendant	1	2	8
4. Consumer requests an individual provider...	1	2	8

5. Other _____

_____

D4. Under what circumstances, if any, can a relative be paid for attendant care services?

	Yes	No	D/K
1. Does not reside in same house if related by blood (includes spouse)	1	2	8
2. Is not the family member/spouse legally responsible for the disabled person	1	2	8
3. Is prevented from working outside the home because no other attendant available	1	2	8
4. Is prevented from working outside the home because no one else capable of caring for disabled individual	1	2	8

5. Other _____

_____

SKIP TO HERE

D5. What is the hourly wage for self-employed individual providers?

$_____

D6. What benefits do self-employed individual providers receive?

	Yes	No	Varies	D/K
1. Vacation Pay	1	2	3	8
2. Sick leave	1	2	3	8
3. Health Insurance	1	2	3	8
4. Worker's Compensation	1	2	3	8
5. Social Security	1	2	3	8
6. Unemployment Compensation	1	2	3	8
7. Transportation Costs	1	2	3	8

D7. What skill level is required for the people who provide direct attendant services?

	Yes	No	D/K
1. Trained by client/consumer	1	2	8
2. LPN	1	2	8
3. Home Health Aide	1	2	8
4. Graduate of agency training program	1	2	8
5. Other _____ (specify)			

D8. Who hires and fires the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

D9. Who pays the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

IF ONLY SELF-EMPLOYED ARE PROVIDERS, SKIP TO E1
IF CONTRACT AGENCIES ARE PROVIDERS, CONTINUE
IF LOCAL GOVERNMENT UNITS ARE PROVIDERS, SKIP TO D17

SKIP TO HERE FOR CONTRACT AGENCIES

D10. Which of the following types of contract agencies are there under this program?

	Yes	No	D/K
1. Certified Home Health Agencies	1	2	8
2. Private, non-profit	1	2	8
3. Private for profit	1	2	8
4. Local Government Units	1	2	8

5. Other _____

_____

D11. What is the average hourly reimbursement you pay to contract agencies?

$_____

$_____

$_____

D12. What is the average hourly pay range of the people who provide direct attendant care?

$_____

$_____

$_____

D13. What benefits do contract agency attendants receive?

	Yes	No	Varies	D/K
1. Vacation Pay	1	2	3	8
2. Sick leave	1	2	3	8
3. Health Insurance	1	2	3	8
4. Worker's Compensation	1	2	3	8
5. Social Security	1	2	3	8
6. Unemployment Compensation	1	2	3	8
7. Transportation Costs	1	2	3	8

D14. What skill level is required for contract agency attendants?

	Yes	No	D/K
1. Trained by client/consumer	1	2	8
2. LPN	1	2	8
3. Home Health Aide	1	2	8
4. Graduate of agency training program	1	2	8
5. Other _____ (specify)			

D15. Who hires and fires the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

D16. Who pays the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

IF LOCAL GOVERNMENT UNITS NOT PROVIDERS, SKIP TO E1

SKIP TO HERE FOR LOCAL GOVERNMENT EMPLOYEES

D17. What is the hourly wage for attendants who are government employees?

$ _____

D18. What benefits do goverment employed attendants receive?

	Yes	No	Varies	D/K
1. Vacation Pay	1	2	3	8
2. Sick leave	1	2	3	8
3. Health Insurance	1	2	3	8
4. Worker's Compensation	1	2	3	8
5. S al Security	1	2	3	8
6. Unemployment Compensation	1	2	3	8
7. Transportation Costs	1	2	3	8

D19. What skill level is required for goverment employees who provide direct attendant services?

	Yes	No	D/K
1. Trained by client/consumer	1	2	8
2. LPN	1	2	8
3. Home Health Aide	1	2	8
4. Graduate of agency training program	1	2	8
5. Other _____ (specify)			

D20. Who hires and fires the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

D21. Who pays the attendant?

	Yes	No	D/K
1. Consumer	1	2	8
2. Government Agency	1	2	8
3. Contractor	1	2	8

E. ADMINISTRATION

E1. Which of the following are the basis for determining the hours and types of services to be provided to each recipient?

	Yes	No	D/K
1. Physician's recommendation	1	2	8
2. Functional ability (ADLs)	1	2	8
3. Accessibility of environment	1	2	8
4. Plan of care less costly than institutionalization	1	2	8
5. ICF eligible	1	2	8
6. S rvices Needed	1	2	8

7. Other _____

_____

E2. Who makes the final decision on hours and types of services provided?

	Yes	No	D/K
1. Case Management Agency Assessment Team	1	2	8
2. Program Director	1	2	8
3. Independent Living Program	1	2	8
4. Vocational Rehabilitation Couselor	1	2	8

5. Other _____

_____

E3. Is medical supervision (nurse, physican or other licensed practitioner) required for any of the services?

	Yes	No	D/K
1. For all services	1	2	8
2. Some services _____	1	2	8
_____ (specify)			
3. None	1	2	8

IF NONE, SKIP TO F1

E4. How often is this supervision required?

	Yes	No	D/K
1. Once a month or more	1	2	8
2. Once every 2 months	1	2	8
3. Each quarter	1	2	8
4. Once every 6 months	1	2	8
5. Once a year	1	2	8

SKIP TO HERE

F. CLIENTELE

F1. For FY 1984 or the latest year figures available FY_____(specify), what is the unduplicated count of recipients of the following: **(REFER TO BI FOR DEFINITIONS)**

1. Personal Care Services ..... _____
2. Domestic Services ..... _____
3. Related Services ..... _____
4. All Attendant Care Services ..... _____
5. Total Program (includes attendant care plus _____) _____ N/A

F2. Approximately what percentage of the program's clientele in FY 1984 or FY _____ (specify) was: **IF RESPONDENT CAN'T BREAK DOWN FIGURES INTO THESE AGE CATEGORIES, USE THEIR CATEGORIES AND RECORD ON DOTTED LINE**

1. Under 18 years of age ..... _____%
2. 18-64 years old ..... _____%
3. 65-74 years old ..... _____%
4. 75 and older ..... _____% N/A

F3. What percentage of the program's clientele in FY 1984 or FY _____ (specify) was:

1. male ..... _____%
2. female ..... _____% N/A

F4. What percent age of the program's clientele for FY 1984 or FY _____ (specify) was:

1. Black ..... _____%
2. Hispanic ..... _____%
3. Native American ..... _____%
4. Asian ..... _____%
5. White ..... _____% N/A

F5. What was the average income of the program's clients in FY 1984 or FY _____ (specify)?

$_____ N/A

F6. What was the percentage of clients receiving income from the following in FY 1984 or FY _____?
(specify)

1. Social Security Surviror's Benefits ..... _____%
2. Social Security Retirement Benefits ..... _____%
3. SSI ..... _____%
4. SSDI ..... _____%
5. Veteran's Benefits ..... _____%
6. Private Retirement ..... _____%
7. Earned income ..... _____%
8. Family ..... _____%
9. AFDC ..... _____%
10. Other _____ _____% N/A
(specify)

F7. What was the average number of hours of attendant care per week that people received?

_____ N/A

F8. How many people in FY 1984 did not enter institutions or left institutions or nursing homes as a result of this program?

_____ N/A

F9. What is your estimate of the number of people per year who could leave institutions or nursing homes in your state, if attendant care programs were expanded?

_____ N/A

G. EXPENDITURES

G1. For FY 1984 or the latest year figures are available (FY _____) (specify), what was the total dollar amount or percent spent for: **(REFER TO BI FOR DEFINITIONS)**

1. Personal Care Services: $_____ _____%
2. Domestic Services: $_____ _____%

3. Related Services: $_____ _____%

4. All attendant care services: $_____ _____%

5. The total program (includes attendant care plus _____ _____) $_____ _____%

G2. For FY 1984 or FY _____ (specify) which of the following are the sources of funds for the program and the dollar amounts that come from each source?

A. FEDERAL SHARE ONLY (Does not include match)

1. Vocational Rehabilitation

a) Title VII A ..... $_____ _____%

b) Title VII B ..... $_____ _____%

2. Title XVIII (Medicare) ..... $_____ _____%

3. Title XIX (Medicaid) ..... $_____ _____%

4. Title XIX Waiver ..... $_____ _____%

5. Title XX (Social Services Block Grant) ... $_____ _____%

6. Title III ..... $_____ _____%

7. Other Federal: (specify)

_____ $_____ _____%

B. NON-FEDERAL (Including NON-FEDERAL match)

1. State Funds ..... $_____ _____%

2. County Funds ..... $_____ _____%

3. Municipal Funds ..... $_____ _____%

4. Private Funds ..... $_____ _____%

5. Client Contributions ..... $_____ _____%

6. Other Non-Federal: (specify)

_____ $_____ _____%

C. TOTAL FEDERAL AND NON-FEDERAL **(SHOULD BE SAME AS QG1 (4) ABOVE)** $_____ _____%

G3. For FY 1984 or the latest year figures are avaiable FY _____ (specify), what are the number of hours of service delivery for: **(REFER TO B1, for definitions) (IF AGENCY USES DIFFERENT UNIT MEASURE CONVERT TO HOURS AS ACCURATELY AS POSSIBLE)**

1. All attendant care services: _____hrs.

2. Total program (including _____ _____) _____hrs.

G4. Have any studies been done on the cost effectiveness of this program?

Yes	 1	
No	 2	
D/K	 8	**(IF NO or D/K, SKIP TO G6)**

G5. Could you send us a copy?

Yes	 1	
No	 2	
D/K	 8	**(IF YES, GIVE WID'S ADDRESS)**

SKIP TO HERE

G6. Have any studies been done in your state on the extent of need for attendant care services?

Yes	 1	
No	 2	
D/K	 8	**(IF NO OR D/K, SKIP TO H1)**

G7. Could you send us a copy?

Yes	 1	
No	 2	
D/K	 8	**(IF YET, GIVE WID ADDRESS)**

SKIP TO HERE

H. EVALUATION

H1. What are the program's strong points?

_____

_____

_____

_____

_____

H2. What are the program's weak points?

_____

_____

_____

_____

_____

H3. What changes in the program are being contemplated?

_____

_____

_____

_____

_____

(IF AGENCY ADMINISTERS ANOTHER PROGRAM, PROCEED TO NEW FORM, OTHERWISE)

H4. Do you know of any other attendant programs in your state, in particular waiver programs?

_____

_____

Thank you very much for answering our questions.

WORLD INSTITUTE ON DISABILITY
1720 OREGON STREET
BERKELEY, CALIFORNIA 94703
(415) 486-8314
ATTN: DR. SIMI LITVAK

C1a. What are the disabilities of the people who are eligible to receive services from this program?

	Yes	No	D/K
1. Physical Disability.....	1	2	8
2. Brain Injury.....	1	2	8
3. Mental Illness.....	1	2	8
4. Mental Retardation.....	1	2	8
5. MR, CP, Autism, Epilepsy.....	1	2	8
6. DD (broadest definition).....	1	2	8

7. Other_____

F1a. What are the disabilities of the people who receive services from this program?

	Yes	No	D/K
1. Physical Disability.....	1	2	8
2. Brain Injury.....	1	2	8
3. Mental Illness.....	1	2	8
4. Mental Retardation.....	1	2	8
5. MR, CP, Autism, Epilepsy.....	1	2	8
6. DD (broadest definition).....	1	2	8

7. Other_____

THE WORLD INSTITUTE ON DISABILITY (WID) is a private, non-profit 501(c)(3) corporation focusing on major policy issues from the perspective of the disabled community. It was founded in 1983 by persons who have been deeply committed to the Independent Living Movement. Its mission is to promote the health, independence, well-being and productivity of all persons with disabilities. It is funded by foundation grants, technical assistance contracts and individual donations.

WID is a research and information center focusing on five policy and program areas which have significant impact on people with disabilities:

****Attendant Services:*** WID is studying the availability of attendant services around the country and has proposed policy recommendations in this area. It operates a national resource center providing information and technical assistance.

****International Development of Independent Living:*** It has been said that Independent Living is "the hottest new American export today." WID is actively involved in promoting international relations among disabled communities and has hosted visitors from twenty-five countries.

****Public Education:*** WID believes that the general public, disabled people and professionals in the fields of health care, aging, education, housing, job development and transportation need accurate information on disability and independent living. WID is also engaged in consultation and education with synagogues and churches on issues of architectural and attitudinal accessibility for elderly and disabled persons who wish to participate fully in the life of their religious communities.

****Aging and Disability:*** WID has identified the interface between aging and disability as one of its priority areas. It is engaged in ongoing work to build linkages between the disabled and elderly communities. In 1985, WID co-sponsored a major national conference titled, "Toward a Unified Agenda: Disability and Aging."

****Immunization and Injury Prevention:*** The polio virus has once again become a threat to people throughout the world. WID is determined to help eliminate the spread of polio by working with the United Nations and other organizations to make universal immunization a reality. In addition, WID is committed to the prevention of all disabling injuries, diseases and conditions.

Other attendant service publications which can be ordered from the World Institute on Disability, 1720 Oregon Street #4, Berkeley, California 94703:

**Descriptive Analysis of the In-Home Supportive Services Program in California* ($10). Describes one of the most innovative programs in the country. Examines the history of the 25-year-old program, how it operates, who it serves, and its problems.

**Swedish Attendant Care Programs for the Disabled and Elderly: Descriptions, Analysis and Research Issues from a Consumer Perspective* by Adolf Ratzka, Ph.D., published by the World Rehabilitation Fund, 1985 ($3). A consumer-based analysis of the attendant services system in Sweden by an economist who is a user of personal assistants.

*"Report on National Attendant Care Symposium" 1985 ($3). Proceedings from a national meeting sponsored by the National Council of the Handicapped. Includes recommendations for a national policy for attendant services along with recommended changes in existing legislation.

*"Attendant Services, Paramedical Services, and Liability Issues" (Free). Explores the issue of liability of providers of different skill levels performing personal service tasks. Gives consumer-based perspective along with data on how various states deal with the issue.

*"Summary of Federal Funding Sources for Attendant Care" by Hale Zukas (Free). Overview of the provisions for attendant services under Medicare, Medicaid, Social Service Block Grant, The Rehabilitation Act, and Title III of the Older American's Act

*"The Case for a National Attendant Care Program" by Hale Zukas (Free). An analysis of the federal funds presently utilized to finance attendant services, their inadequacy to fulfill the need, and the need for a national entitlement program.

*"Attendant Service Programs that Encourage Employment of Disabled People" (Free). Brief state by state description of programs encouraging employment, giving information on eligibility criteria, administrating agency, funding source, utilization and expenditures.

*"Ratings of Programs by Degree of Consumer Control" (Free). Ratings of each program's degree of consumer control based on the National Council on the Handicapped's ten-point criteria.